Joana Catarina da Silva Peixoto

"What is Cerebral Palsy?" Examining Elementary School Students' Knowledge on the Phenomenon

Outubro 2017

Universidade do Minho
Escola de Psicologia

Joana Catarina da Silva Peixoto

**"What is Cerebral Palsy?"
Examining Elementary School
Students' Knowledge on the
Phenomenon**

Dissertação de Mestrado
Mestrado Integrado em Psicologia

Trabalho efetuado sob a orientação de
**Professor Doutor Pedro Rosário
Professora Doutora Paula Magalhães**

Outubro 2017

DECLARAÇÃO

Nome: Joana Catarina da Silva Peixoto

Endereço eletrónico: _____

Número de Cartão de Cidadão:

Título da dissertação: "What is Cerebral Palsy?" Examining Elementary School Students' Knowledge on the Phenomenon

Orientador: Professor Doutor Pedro José Sales Luís Fonseca Rosário
Orientador: Professora Doutora Paula Cristina Soares Magalhães Silva Correia

Ano de conclusão: 2017

Designação do Mestrado: Mestrado Integrado em Psicologia

É AUTORIZADA A REPRODUÇÃO INTEGRAL DESTA DISSERTAÇÃO APENAS PARA EFEITOS DE INVESTIGAÇÃO, MEDIANTE DECLARAÇÃO ESCRITA DO INTERESSADO, QUE A TAL SE COMPROMETE.

Universidade do Minho, 13/10/2017

Assinatura: _____

Index

Index for figures

Agradecimentos

Eu não achava que esta página viesse a ser muito importante, mas durante o caminho que fiz para completar este trabalho, fui percebendo que ia deixando de ser um trabalho só meu. Com uma alegria que não cabe no peito, orgulho-me de apresentar esta investigação. Mas o caminho não foi fácil, e só chego à etapa final porque tenho a graça de viver rodeada de amigos e família que são a minha rocha! E vale a pena apontar aqui o nome de tantos que me encheram de coragem...

Aos meus orientadores agradeço a disponibilidade para me ajudarem a fazer deste o melhor trabalho possível, ensinando-me que consigo realizar um bom trabalho, mesmo que o coração e a missão não estejam completamente alinhados. Agradeço ao GUIA, especialmente à Armanda pelo que ensinou com tanto amor sobre a paralisia cerebral e à Tânia que sempre com muita confiança e paciência me explicou tudo o que eu precisava de saber para analisar os meus dados.

À Andreia e à Beatriz, um obrigada eterno porque dividir preocupações e alegrias é sempre melhor do que guardá-las só para mim.

Aos meus pais e ao meu irmão quero agradecer todos os dias. Porque depois de dias difíceis não há nada melhor do que voltar para casa e perceber que por muito difícil que seja o dia, sou abençoada com a alegria do amor.

Aos meus amigos! Ao grupo de animadores do CAB, à Rita e à Juca! Obrigada por tornarem este último ano mais leve, e sobretudo por me fazerem sentir plenamente realizada só por vos ter comigo.

À Andreia e à Gabi! As gargalhadas, aventuras, lágrimas, e muito mais, destes 5 anos são o melhor que levo deste curso. E agora vamos continuar por novos caminhos de mãos dadas.

Ao Tiago, este meu coração cheio de gratidão também é dele. Ensina-me a ser paciente, a acreditar um bocadinho mais em mim, a olhar da melhor perspectiva! Partilhar a vida assim faz todo o sentido.

Vive feliz. Vive em paz. Que nada seja capaz de te tirar a paz.
Nem o teu cansaço. Nem as tuas falhas.
E no fundo do teu coração coloca tudo aquilo que te enche de paz.
Por isso, quando te sentires desanimado e triste, adora e confia.
P. Pierre Teilhard de Chardin, sj

Outubro 2017

"O que é a Paralisia Cerebral?" Análise do Conhecimento de Alunos do Ensino Básico sobre

o Fenómeno

Resumo

A paralisia cerebral é a deficiência física mais comum na infância. Apesar dos comprometimentos motores e secundários, as crianças com paralisia cerebral estão integradas no sistema de educação. Contudo, investigações prévias mostram que estas crianças nem sempre estão bem integradas na escola e que atitudes negativas para com esta condição clínica estão relacionadas com falta de conhecimento. Esta investigação tem como objectivo analisar o conhecimento de alunos do ensino básico sobre a paralisia cerebral. Foram analisadas 80 definições de paralisia cerebral escritas por 80 estudantes do 4º e 5º ano. Os resultados revelaram que a maioria das respostas são incorrectas porque os participantes confundiram a paralisia cerebral com outras condições ou indicaram que a origem do problema está na paralisação do cérebro. Por outro lado, as respostas consideradas correctas revelaram ser muito incompletas no seu conteúdo. Os resultados também mostraram que estudantes com experiência pessoal com alguém com paralisia cerebral fornecem mais respostas correctas. Estes resultados sugerem que existe necessidade de fornecer informação aos alunos sobre a paralisia cerebral e as dificuldades de uma criança com esta condição. Espera-se que aumentando o conhecimento dos alunos sobre a paralisia cerebral, ajude à integração na escola das crianças com esta condição e promova o seu envolvimento.

Palavras-chave: paralisia cerebral; conhecimento; alunos do ensino básico; estudo qualitativo

Outubro 2017

What is Cerebral Palsy?" Examining Elementary School Students' Knowledge on the
Phenomenon

Abstract

Cerebral palsy is the most prevalent physical disability during childhood. Globally, the
number of children with disabilities being integrated into the general school system is raising.
Still, previous studies have reported that these children are not always well integrated in
school and that negative attitudes towards people with these conditions may be linked to lack
of knowledge. This research aims to analyze elementary school students' knowledge about
cerebral palsy. Eighty definitions of cerebral palsy were provided by students from the 4th
and 5th grades. Findings indicate that the majority of responses are incorrect because the
participants confounded cerebral palsy with other conditions or indicated the origin of the
impairments is in a brain which is paralyzed. Conversely, the correct responses were very
incomplete regarding their content. Data also showed that students with personal experience
with someone with cerebral palsy provided more correct definitions than their counterparts
without this experience. These results indicate the need to provide information to students
about cerebral palsy and the difficulties of children with this condition. Raising students'
knowledge on cerebral palsy is expected to help integrate children with this condition in
school and promote their school engagement.

Keywords: cerebral palsy; knowledge; elementary students; qualitative study

Running head: "WHAT IS CEREBRAL PALSY"

"Cerebral Palsy is to have a burnt neuron".

This is a candid description of Cerebral Palsy (CP) from the point of view of a 10-year-old when prompted with the question, "What is CP?". This definition reveals the general lack of knowledge about a disorder that is the most common childhood physical disability (Novak et al., 2012; Rosenbaum et al., 2007; Sankar & Mundkur, 2005). The diagnosis of CP is determined by the presence of motor and postural impairments, and associated impairments, due to permanent brain lesions (Rosenbaum et al., 2007). Despite these constraints, globally, children with this disability are being integrated in the general school system due to the increasing policies that support their integration (NCLB, P.L: 107-110; Almeida, 2002). Still, notwithstanding these efforts, prior research indicates problems regarding the integration of children with CP in mainstream schools (e.g., poor social adjustment, see Ison et al., 2010; Lindsay & Mcpherson, 2012). Ignorance about this clinical condition may help explain mainstream students' behaviors towards their counterparts with CP; so, the current study aimed to examine mainstream fourth and fifth graders' knowledge on CP. To learn further about mainstream students' awareness on this clinical condition may help understand how children with CP are looked by their peers. This corpus of knowledge is expected to help school administrators, teachers, and therapists design contents to use in class or awareness-raising interventions aiming to favor the integration of children with CP in school.

Theoretical background

What is Cerebral Palsy?

The classic definition of CP dates back to 1964, when Bax described CP as a permanent disorder of movement and posture caused by defect, or non-progressive lesion, in the brain in early stages of life. This definition does not include a reference to secondary impairments, such as sensory, cognitive, and behavioral deficits (Rosenbaum et al., 2007). Therefore, to establish a more inclusive and consensual definition, the document "Definition and Classification of Cerebral Palsy, April 2006" conceptualized CP more broadly as:

> (…) a group of permanent disorders of the development of movement and posture, causing activity limitation, which are attributed to non-progressive disturbances that

occurred in the developing fetal or infant brain. The motor disorder of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior; by epilepsy, and by secondary musculoskeletal problems. (Rosenbaum et al., 2007, p.9).

Nowadays, CP is considered the most common cause of childhood physical disability (Novak et al., 2012; Rosenbaum et al., 2007; Sankar & Mundkur, 2005) and recent data indicates that the prevalence of this disorder is of 2 children per 1000 live births (Oskoui, Coutinho, Dykeman, Jetté, & Pringsheim, 2013). The diagnosis of CP can be determined by the nature of the motor impairments, which are present due to neuromuscular and musculoskeletal deficits (Ostensjø, Carlberg, & Vøllestad, 2004). These deficits can be categorized as follows: spastic, dyskinetic, ataxic, and mixed. The spastic type is the most prevalent (72% - 91%) and it involves the pyramidal cells causing a higher muscular tonus than what is typical (Odding et al., 2006). Dyskinesia involves extra pyramidal cells causing abnormally lower muscular tonus as well as involuntary movements. The ataxic type is also related to a low muscular tonus and problems of balance and coordination. The mixed form subsumes a combination of the types described above (Sankar & Mundkur, 2005). Additionally, other way of classifying CP is through the topographic classification which determines the anatomic distribution of the motor impairments, the classifications being quadriplegia, diplegia, and hemiplegia (Rosenbaum et al., 2007). Quadriplegia is characterized by a four-limbs impairment, diplegia corresponds to major motor difficulties in the lower limbs comparing to the upper ones, and hemiplegia implies a unilateral impairment in which the upper limbs have more difficulties compared to the lower ones (Sankar & Mundkur, 2005).

In addition to the motor impairments, CP has secondary associated impairments, such as cognitive, lingual, visual, auditory deficits, as well as presence of epilepsy (Sankar & Mundkur, 2005). Regarding the cognitive impairments, their prevalence varies according to the type of CP. For example, about 40% of hemiplegic children show normative capacities, as they correspond to an IQ above 70; whereas, in general, quadriplegic children tend to display several cognitive impairments. Similarly, lingual, visual, and auditory problems are predominant in quadriplegic children (Odding et al., 2006), being present in 38%, 28%, and 12% of quadriplegic CP cases, respectively (Sankar & Mundkur, 2005). These impairments suggest that some children with CP may need specialized learning support when reaching school age, both inside (e.g., adaptations in the curricula) and outside the classroom (e.g.,

regarding the participation in activities with their peers). Taking these distinctive needs into account becomes increasingly important, as the opportunities for children to integrate the general school system are increasing worldwide (Schenker, Coster, & Parush, 2005; Peters, 2007).

Integration of Individuals with CP in Mainstream School

The integration of children with CP in the general school system is becoming a reality in many countries. In the United States, for example, *The No Child Left Behind Act of 2001*, ensures that every child has the opportunity to benefit from a fair, equal, and quality education, and is able to reach a minimum proficiency on academic achievement requirements (NCLB, P.L: 107-110). Similarly, in Portugal, the Decree-law 319/91, of 23 of August introducing the concept of "special educational needs" (SEN) was a significant milestone for the process of inclusion of disabled children in regular education. This legislation enabled a common learning and recreation space to all students while taking into account the specific curricula features to accommodate the needs of children with SEN (Almeida, 2002). With the increase of policies towards integration, it is important to understand how children in mainstream classes comprehend the nature of the clinical condition of children with SEN. For example, learning about students' awareness about CP allows gathering a corpus of knowledge that may help educators organize sessions to discuss the misunderstandings and inaccuracies associated with this clinical condition. Deliberate efforts to increase knowledge and address misunderstandings are expected to encourage positive peer relationships (e.g., Ison et al., 2010; Krahe & Altwasser, 2006; Rillotta & Nettelbeck, 2007), which favors positive social skills (Lindsay & Mcpherson, 2012), low loneliness, and high social satisfaction (Ladd, Kochenderfer, & Coleman, 1997; Parker & Asher, 1993).

People with disabilities tend to be "identified in an exaggerated fashion based on one characteristic" (Altman, 1981, p. 321). For example, children with CP present particular features regarding movement and posture that can contribute to generate misconceptions about their real difficulties (e.g., the expected presence of cognitive impairments). Besides movement and posture impairments, which have visible cues and are likely to compromise autonomy, children with CP may also present secondary impairments (e.g., sensation, perception, communication) that are likely to influence their performance in basic skills at school (Nadeau & Tessier, 2009).

The limitations faced by children with CP in school (e.g., autonomy in moving around) may lead to a biased choice of interaction in class. Nangle, Erdley, and Gold (1996)

reported that children, between the ages 9 and 12, select the classmates to interact with based on similarities they identify among themselves. For example, similarities in the social status, physical appearance, and behavior (Nangle et al., 1996). Extant research has shown that peers perceive that children with CP show poorer social adjustment than that of children without this condition (Nadeau & Tessier, 2006; Nadeau & Tessier, 2009; Yude & Goodman, 1999). Overall, prior research findings indicate that children with CP may engage in poorer relationships than their peers and, therefore, the integration into mainstream classes may not always be a synonym of good integration among peers.

Knowledge on CP and the lack of

The attitudes towards disabilities are formed based on several indicators being the knowledge on the condition one of the most important (Ison et al., 2010; Shah, 2004). Using open-interviews, Magiati and colleagues (2002) asked children in mainstream classes what they knew about sensory, physical, cognitive, and learning disabilities. Findings indicated that the children's views on disabilities were very broad and the content was sometimes incomplete or erroneous. Importantly, the core knowledge seemed to be built around the most relevant characteristics observed. This may help explain why physical disabilities were the ones children were most aware of. Moreover, participants also tended to attribute physical disabilities to external causes (e.g., accidents) and cognitive disabilities to internal causes (e.g., birth injuries). In addition, children frequently talked about emotional and social implications of disabilities with negative connotations by portraying impaired peers in comparison with their classmates as lonelier, unhappier, and foretelling a more negative future for them.

Focusing on CP, extant findings suggest that the lack of knowledge and poor understanding of CP may play an important role in the formation of negative attitudes towards this condition. These negative attitudes are likely to ground behaviors that promote exclusion and victimization (Ison et al., 2010; Lindsay & Mcpherson, 2012). Specifically, prior research indicates that lack of knowledge about a particular condition is associated with negative attitudes towards that condition (Gillespie-Lynch et al., 2012; Martin, Rowell, Reid, Marks, & Reddihough, 2005), but little evidence has been found regarding CP.

Purpose of the study

This study analyzed elementary school students' knowledge about CP. The study is focused on CP because this condition is the most prevalent physical disability in children (Novak et al., 2012; Rosenbaum et al., 2007; Sankar & Mundkur, 2005). Despite their

impairments, children with CP are increasingly being integrated in the school system (Schenker et al., 2005), participate in the school activities, and interact with typically developing peers. Still, many studies have reported that this assimilation does not, necessarily, result in good integration among peers (Nadeau & Tessier, 2006; Nadeau & Tessier, 2009; Yude & Goodman, 1999). Globally, the negative attitudes towards a condition tend to be linked to a lack of knowledge (Ison et al., 2010; Shah, 2004). This has been the rationale to build disability awareness programs (DAP) (e.g. Ison et al., 2010; Krahe & Altwasser, 2006; Rillotta & Nettelbeck, 2007). These school based interventions address negative attitudes emerging in authentic learning settings (Ison et al., 2010); however, literature has stressed that DAP rarely take into account the participants' prior knowledge about the condition being analyzed (Campbell et al., 2011; Magiati et al., 2002; Woolfson, Woolfson, Mooney, & Bryce, 2008). Consulting students to understand their knowledge about the clinical conditions may help design interventions matching students' educational needs (Campbell et al., 2011), and is expected to improve the efficacy of school-based interventions targeting the promotion of positive attitudes towards people with CP.

Moreover, the current study was focused on elementary students from the fourth and fifth grades. At this developmental stage, students are eager to learn school contents and behavior patterns (Rosário et al., 2016). This is consistent with the work by Weiss (1994) who reported that negative attitudes are developed in early childhood and tend to stabilize with age. Not surprisingly, Shah (2004) suggested that the promotion of students' awareness about disabilities should start at elementary school. Finally, this study also analyzed the accuracy of the answers of children who know someone with CP against children who do not know anyone with CP. This analysis is expected to help understand whether personal experience with someone with CP influences their knowledge on this condition.

Method

Participants

The present study is part of a larger investigation about attitudes towards children with CP, which enrolled 702 children from elementary school. Considering the qualitative nature of the goals of this investigation, the present study included a total of 80 students from the fourth and the fifth grade, between the ages of 9 and 12 ($M = 9.99$, $DP = .67$). From the original pool of participants, 40 students were randomly selected from the group of children who had personal experience interacting with people with CP; and 40 students were randomly

selected from the counter group without personal experience with people with CP, as illustrated in Figure 1 bellow. These students were in the fourth (21.3%) and fifth (78.8%) grades and attended 18 regular classrooms, all from public schools in the north of Portugal. From this pool of students, 50 were boys (62.5%).
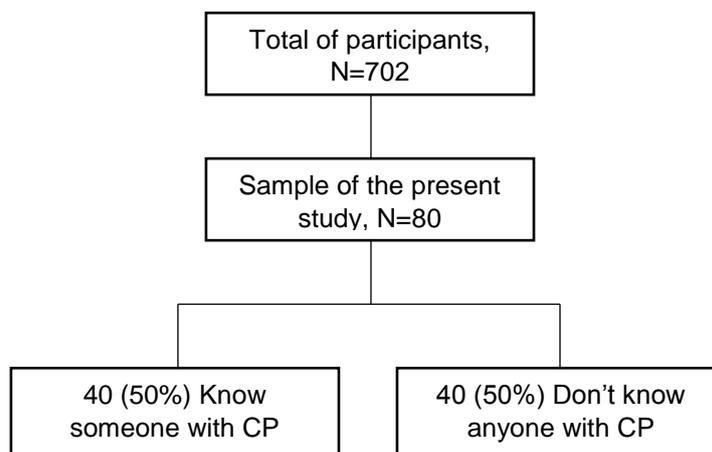
```
                    ┌─────────────────────┐
                    │ Total of participants, │
                    │      N=702           │
                    └─────────────────────┘
                              │
                    ┌─────────────────────┐
                    │ Sample of the present │
                    │    study, N=80       │
                    └─────────────────────┘
                              │
              ┌───────────────┴───────────────┐
    ┌──────────────────┐            ┌──────────────────┐
    │  40 (50%) Know   │            │ 40 (50%) Don't know │
    │  someone with CP │            │  anyone with CP  │
    └──────────────────┘            └──────────────────┘
```

Figure 1. Sample of the present study

Measures and Instruments

Socio-demographic questionnaire. This questionnaire provided information about the gender, age, and school grade of the participants, as well as information regarding whether they knew someone with CP.

Open question. Questionnaires about factual knowledge were found to be a limited methodology to access declarative knowledge on a particular theme or to capture the diversity of conceptions and beliefs on the phenomenon (Campbell et al., 2011). Hence, to surpass this limitation, the open-ended format question "What is Cerebral Palsy?" was presented to children.

Procedure

First, an authorization was obtained from the Ministry of Education and schools were contacted to participate. Afterwards, parental consents asking authorization for their children to participate were sent home. Data collection took place in a regular class. Students were invited by a research assistant to fill in the aforementioned instruments. The research assistant highlighted the need to complete the task individually.

Data analysis

Participants' answers were transcribed verbatim to digital format for later coding, and the analysis was performed with the assistance of the software NVivo. A thematic analysis

was carried out following the steps indicated by Braun and Clarke (2006). The answers were coded based on a codebook purposely adapted for this study. This codebook was built following a deductive and inductive process at a semantic level (Braun & Clarke, 2006). In the deductive approach, the codebook was based on the model by Campbell and colleagues (2011). These authors analyzed each response based on two perspectives: accuracy of the definition and thematic content of the definitions provided by participants. Concerning accuracy of the definition, the responses for autism (the clinical condition examined by Campbell et al., 2011) were coded as correct, incorrect, correct and incorrect, and "don't know". Due to the heterogeneity of impairments that may or may not be associated with CP, in the current research, within the accuracy category two new codes were included: "correct response which consists in a generalization" and "correct and incorrect response which consists in a generalization". The first refers to responses with accurate information relating to impairments that may not be present in every case of CP (e.g., P65: *I think cerebral palsy is a person who cannot walk and due to that uses a wheelchair*). The second indicates responses with both incorrect and correct information that may not be true for every cases of CP (e.g., P9*: It is when our brain suddenly stops. We become unable to talk and speak*).

Regarding the thematic content of the definitions, the following codes, based on the codebook developed by Campbell and colleagues (2011), were considered: (a) general theme; (b) main impairments; (c) secondary impairments; (d) etiology; and (f) comments on how people with disabilities should be treated. A new category was included; (h) comments about the severity of CP. The emergent themes and sub-themes from data were defined taking into account participants' own words (see Appendix A for categories and subcategories).

To enhance the trustworthiness of the findings, two researchers carried out the thematic analysis. Both were trained on the coding scheme and coded independently every answer. After each researcher coded the answers, the inter-rater reliability was assessed and the researchers met to discuss discrepancies found in the coding process. Coding decisions were evaluated per item and considered reliable if: (a) percent agreement ≥80% (Horner et al. 2005) and (b) κ ≥0.75 (excellent reliability; Landis & Koch, 1977). Cohen's Kappa coefficient showed an inter-rater agreement of .97, which is considered as almost perfect (Landis & Koch, 1977). After coding 35 definitions for both groups of participants (i.e. 35 for the group without personal experience and 35 for the group with personal experience), researchers found that further answers produced no changes in the codebook. At this point, data saturation was reached.

Results

Response accuracy and content of the responses

Incorrect responses. Concerning accuracy, the code "incorrect" was attributed to responses with only inaccurate content regarding CP (e.g., P30: *It is when the brain stops*). Most participants answered incorrectly to the open-format question "What is CP?" (35% of wrong answers; 28 out of 80). These responses are incorrect due to erroneous attribution of the cause of CP; this condition was identified as a problem related to the brain itself being paralyzed (e.g., P54: *Cerebral palsy is a person who cannot do anything because the brain has stopped functioning;* P56: *It is the brain stopping suddenly and becoming "like a baby"*). Moreover, a detailed analysis of these incorrect answers allowed to conclude that 53.57% (15 out of 28) confused CP with other problem or disease (e.g., P2: *What I think is that cerebral palsy is someone with depression;* P12: *Cerebral palsy is when people forget [*things*] and need care*).

Interestingly, the descriptions coded as incorrect also refer some aspects that may be associated to CP, but relate them to the incorrect assumptions described above. For example, most of these wrong responses, 60.71%, (17 out of 28) identified lesion or problems in the brain as the cause for CP (e.g., P30: *It is when the brain stops*). Moreover, 35.71% (10 out of 28) referred to the possible presence of cognitive impairments (e.g., P27: *CP is when the brain stops thinking*), and 10.71% (3 out of 28) referred to the possibility of presence of language impairments (e.g., P51: [People] *don't feel their arms, don't talk and may also be unable to eat*).

Correct responses. The code "correct" was assigned to responses with only accurate information about CP (e.g., P79: *Cerebral palsy is a disease in the brain*). Less than one quarter of the answers were completely correct (22.5%; 18 out of 80). Among these, 94.44% (17 out of 18) indicate that CP is a problem or a disease, and 88.89% (16 out of 18) indicate that it may be associated to some problem in the brain (e.g., P5: *I think cerebral palsy is some problem in the brain;* P41: *Cerebral palsy is a problem in the brain, as the name indicates. (...)*). Any of the completely correct answers points out the main impairments of CP, being motor and postural. Only one answer out of 18 (5.56%) indicated the possible presence of secondary impairments, referring exclusively to cognitive difficulties (e.g., P50: *It is someone who is ill from the head*).

Correct responses with generalizations. This code was attributed to definitions with accurate information about CP that corresponded to generalizations of the impairments that

may be present in this condition (e.g., P65: *I think cerebral palsy is a person who cannot walk and due to that uses a wheelchair;* P68: *It is when someone has problems thinking;* P73: *Cerebral palsy is a person who cannot talk very well and cannot have memory like normal people*). Fifteen out of the 80 responses (18.75%) included accurate but generalized content.

Concerning the answers with correct content related to generalizations, 33.33% (5 out of 15) refer to motor impairments (e.g., P44: *It is a handicapped child who uses a wheelchair or not;* P64: *Cerebral palsy incapacitates people from walking, moving (...)*). These answers also refer to secondary impairments to the CP diagnosis: 46.67% (7 out of 15) of the responses indicated cognitive difficulties (e.g., P68: *It is when someone has problems thinking*), and 33.33% (5 out of 15) suggested the presence of language impairments (e.g., P73: *Cerebral palsy is a person who cannot talk very well (...)*).

Correct and incorrect responses with generalizations. The code "correct and incorrect response" was attributed to descriptions that combined accurate and inaccurate information about CP. Frequently, these descriptions provided information that is incorrect, but added information of impairments that may be present in the CP diagnosis (e.g., P9*: It is when our brain suddenly stops. We become unable to talk and speak*). Seven answers out of 80 (8.75%) included correct and incorrect information. Similar to the exclusively incorrect responses, these responses were, partially, considered inaccurate (e.g., CP was mixed with another disease or problem, children identified CP as a problem related to the brain being paralyzed). Nevertheless, there was also correct content: 71.43% (5 out of 7) of these answers linked CP to problems in the brain and 42.86% (3 out of 7) indicated the presence of impairments of movement and posture. They also indicated the presence of secondary impairments such as cognitive (28.57%, 2 out of 7) and language (42.86%, 3 out of 7) difficulties.

"Do not know" responses. Fifteen percent of the answers (12 out of 80) did not address any definition of CP. Students wrote that they did not know what CP is.
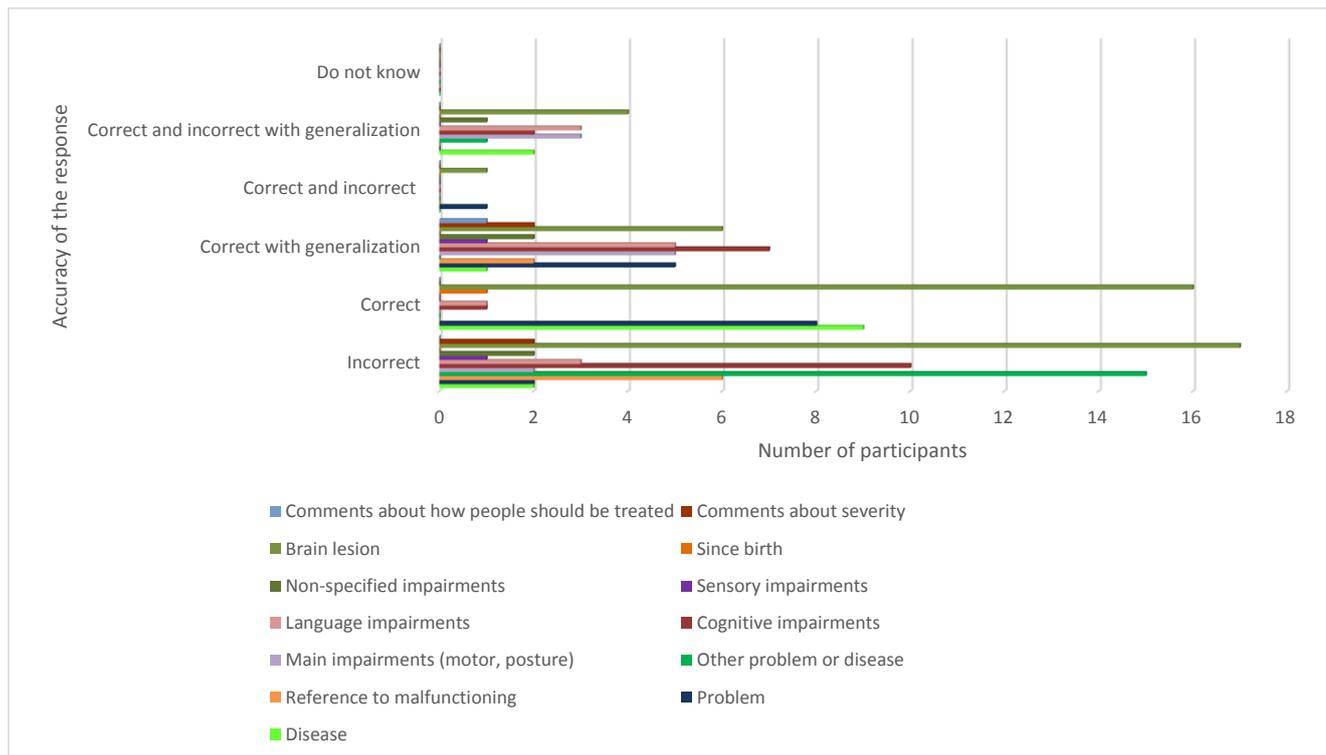
Figure 2. Accuracy of the responses and their content. Each bar represents the number of participants corresponding to each code of accuracy and each color represents a type of response, concerning the content.

Personal experience with CP, response accuracy, and content of the responses

   Participants with personal experience. Concerning the accuracy of the responses provided by participants who know someone with CP, 27.5% (11 out of 40) of the answers were completely correct. A higher percentage, 32.50% (13 out of 40), referred to impairments associated to CP which may not be present in all cases, and for this reason these responses were considered correct with generalizations. A quarter of the answers of participants in this condition (10 out of 40) were incorrect. CP was described as a problem where the brain is paralyzed (e.g., P54: *Cerebral palsy is a person who cannot do anything because the brain has stopped functioning*) or by confusing CP with some other problem or disease (e.g., P61: *I think it is to become paralyzed and fall on the ground. To shake a lot and may or may not have loss of memory*). Moreover, 12.50% (5 out of 40) of the answers hold both correct and incorrect information (e.g., P57: *Cerebral palsy is a psychological disease. I think it is someone who cannot move*). Finally, only 2.50% (1 out of 40) of the answers referred that they do not know what is CP, even though they indicated they knew someone with the condition.

Within this group, 77.5% (31 out of 40) of the answers described CP as a problem, disease, disability or malfunction (e.g., P55: *It is a disability in which half of the brain cannot work*), and 62.50% (25 out of 40) referred the association to some lesion in the brain (e.g., P76: *CP is having a problem in the brain*; P79: *CP is a disease in the brain*). Regarding secondary impairments, 27.50% (11 out of 40) indicated the presence of cognitive difficulties (e.g., P52: *CP is a disease which, as the name indicates, delays the brain and the capacity to think;* P68: *It is when someone has problems thinking).* Also, 22.50% (9 out of 40) indicated the presence of language impairments (e.g., P77: *Cerebral palsy is a person who cannot speak very well*). Lastly, only 20% (8 out of 40) of the answers of participants with personal experience with a person with CP mentioned motor and postural impairments (e.g., P58: *(...) these people become disabled and cannot move their arms, legs and cannot speak;* P69: *Cerebral palsy is a person (...) who cannot move as well as other people and uses a wheelchair*).

Participants without personal experience. Concerning the accuracy of the responses provided by participants without personal experience with CP, 45% (18 out of 40) of their answers contained incorrect content. These responses are similar to those provided by participants with personal experience. For example, describe CP as a problem in which the brain is paralyzed. There are also responses with completely correct content (17.50%, 7 out of 40), which describe CP as a problem or condition associated with the brain, 5% (2 out of 40) of responses with correct information that correspond to generalizations, and 5% (2 out of 40) of answers containing both correct and incorrect information. Finally, in 27.5% (11 out of 40) of the answers participants wrote that they do not know what CP is.

Similar to the group with personal experience, the reference to CP as a disease, problem or malfunctioning (e.g., P6: *For me cerebral palsy is a person whose brain is more delayed than ours*) is the most frequent content (62.5%, 25 out of 40), followed by the reference to the cause associated to some brain lesion (e.g., P28: *It is a person who has problems in the head*) indicated in 47.50% (19 out of 40) of the answers of participants who did not know someone with CP. The pattern repeats itself concerning secondary impairments, with more frequent references to cognitive impairments (22.50%, 9 out of 40) (e.g., P17: *It is people with more needs concerning their brain who are not always thinking what they are supposed to)*, followed by 7.50% (3 out of 40) of the answers indicating the presence of language impairments (e.g., P14: *It is when the brain stops and people cannot talk or do many things*). Only 5% (2 out of 40) of the answers indicated the presence of motor and postural

impairments, by referring that it is linked to paralysis-related conditions, such as the inability to walk. Once more, amongst these answers, 27.50% (11 out of 40) confounded CP with other problem or disease (e.g., P1: *I think cerebral palsy is a person who does not remember the things he did an hour ago*; P2: *What I think is that cerebral palsy is someone with depression*).
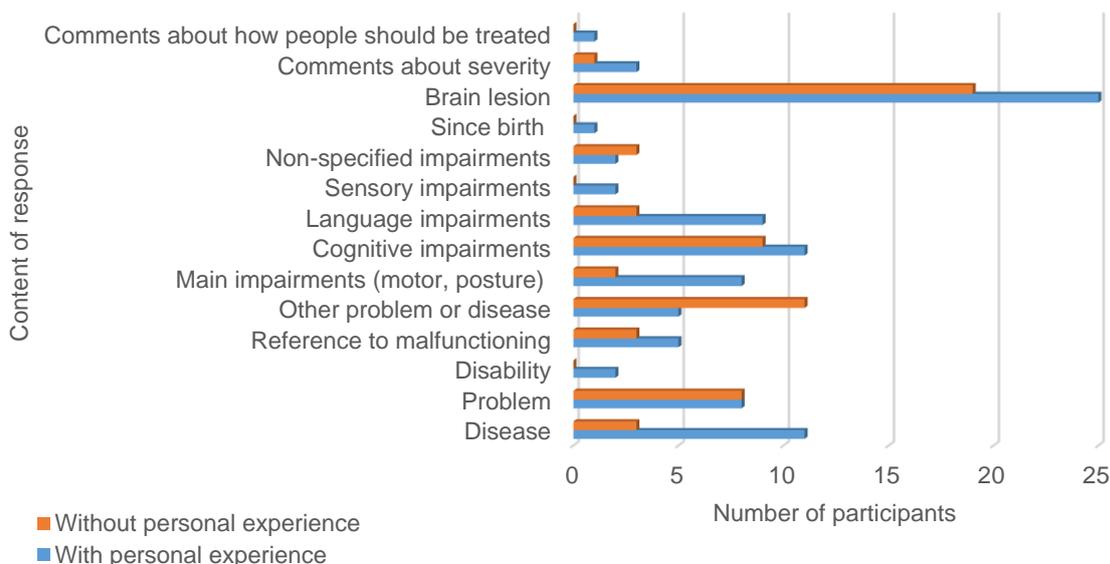

Figure 3. Content of the responses and personal experience with CP. Each bar represents the number of participants who referred each content category and each color represent the personal experience with CP.

Discussion

This study aimed to learn elementary school children's knowledge about CP. Overall, findings indicate that the majority of the responses were incorrect. The descriptions tended to define CP as a problem related to the brain being paralyzed. This type of responses may be related to the term "Cerebral Palsy" used to characterize this clinical condition, which may prompt children to translate literally into their own words their understanding of the condition (P30: *It is when the brain stops*). Moreover, participants' incorrect answers frequently mixed CP with other clinical conditions. The social cognitive literature may help understand these latter findings (e.g., Navarro & Arechavaleta, 2017). When required to make quick judgments, people frequently use heuristics; which are strategies used to make quick and frugal decisions of judgement, at the expense of ignoring part of the information (Gigerenzer & Gaissmaier, 2011). Tversky and Kahneman (1974) stood out for their work in this domain, and started by describing three heuristics of judgement: availability, representativeness, and

adjustment. From these three, the availability and representativeness heuristics may be particularly useful to help interpret the present results. The heuristic availability, for example, describes how people tend to judge the probability of an event, or frequency of some group, based on the easiness in which it comes to their mind. The most common event, or group, usually is more likely to be saved in memory and also more likely to be retrieved from it (Tversky & Kahneman, 1974). To illustrate, a recent study about immigration beliefs (Navarro & Arechavaleta, 2017) reported that the majority of participants believed that emigrant Africans used to arrive to Europe in small boats. Despite only a small percentage of the immigrants use this mean of transportation to enter Europe, the images in television and internet on this phenomenon are prevalent, and people are likely to remind them easily (Navarro & Arechavaleta, 2017). Similarly, in the present study, when asked to make a quick judgment on what is CP, children may have focused their attention on the label of this condition: 'Cerebral Palsy - brain paralyzed'; or they may have recalled problems or disabilities familiar and emotionally meaningful to them, but not related to CP (e.g., P2: *What I think is that cerebral palsy is someone with depression.*)

Regarding the representativeness heuristic, it states that people make judgments about which category something belongs to, based on some similarity with the other elements of that category (Tversky & Kahneman, 1974). The study by Navarro and Arechavaleta (2017) asked participants to estimate the likelihood of the nationality of one person based on the description as enthusiastic and funny. Participants responded it was more likely for that person to be Italian than German, generalizing the characteristics enthusiastic and funny to the Italian people. In the present study, children answering the question "What is CP?" may have relied on examples of specific impairments they were aware of and generalized those impairments to all people with CP. This might help explain the considerable number of correct, but incomplete responses, whereas secondary impairments were commonly absent in the responses. When present, references to secondary impairments were likely to be generalizations of impairments that may be present in a case of CP (e.g., P73: *Cerebral palsy is a person who cannot talk very well and cannot have memory like normal people.*). These generalizations mentioned mainly cognitive, language, and motor impairments. Despite accurate, the descriptions of impairments were focused on extreme cases of the condition (e.g., P58: *(...) these people become disabled and cannot move their arms, legs and cannot speak*). These findings are consistent with Campbell and colleagues' (2011) data on autism. That is, in the present study children show ignorance about the broad definition of CP (i.e. a

group of permanent disorders of movement and posture frequently accompanied by secondary impairments) (Rosenbaum et al., 2007). Therefore, the generalization of impairments and the description of extreme possibilities of CP may also be interpreted as quick and frugal judgments that ignore part of the information about CP.

Despite many answers being correct, these were very incomplete regarding their content because CP was only referred to as a disease or a problem related to some injury in the brain. Neither main (i.e. motor and postural) or secondary (e.g., cognitive, language, sensory) impairments were mentioned by the participants. Additionally, the correct answers were included in the categories general theme and etiology. This data is consistent with findings reporting children knowledge about illness (Campbell et al., 2011; Fox & Barrett, 2008).

Concerning personal experience with CP, results show that the students who know someone with this disorder provide more correct answers than those who are not aware of cases of CP. This suggests that knowing someone with this disability may influence children's extant knowledge about CP. This knowledge may prevent for confounding CP with other conditions and also result in a more elaborated definition, comparing to naïve descriptions of the condition (i.e. "CP is having a brain which is paralyzed"). These results are consistent with literature reporting that the contact with people with a disability not only increases the knowledge about the disability (Ison et al., 2010), but also improves the attitudes towards the condition (e.g., Ison et al., 2010; Krahe & Altwasser, 2006; Rillotta & Nettelbeck, 2007).

Regarding the content of the responses, the definitions provided by both groups (children with and without knowledge of people with PC) were very similar; for both groups the most referenced categories were the general theme and etiology, followed by possible cognitive difficulties. The most salient difference between groups lays in the reference to motor or postural impairments, both more prevalent in the group with personal experience, which may indicate a higher awareness of what defines CP. However, only a small percentage of responses mentioned motor or postural impairments, especially when considering that these are the main impairments to diagnose CP (Ostensjø, Carlberg, & Vøllestad, 2004). All considered, the knowledge of the elementary students about CP may be characterized as very broad, incomplete, and often inaccurate, which is consistent with the findings by Magiati and colleagues (2002).

Implications for Practice and Peer Education about CP

Findings indicate a lack knowledge about this disability, which may contribute to quick and frugal judgments of what is CP, leading to confusion and generalizations about the definition and the consequences of the condition. This data may help explain children with CP poor social adjustment in school (Nadeau & Tessier, 2006; Nadeau & Tessier, 2009; Yude & Goodman, 1999) and suggest clear educational implications. The most direct implication of this study is the need to disclose information and raise students' awareness about CP. Educators could consider embedding the definition of CP in the content of specific disciplines of the general education (Rosário, Lourenço, Paiva, Núñez, González-Pienda, & Valle, 2012). This curricular infusion approach is likely to contribute to improve the knowledge about the topic and favor positive attitudes towards the phenomenon (Cummings, Cassie, Galambos, & Wilson, 2006; Rosário et al., 2016). The focus on the definition of the clinical condition may help prevent misconceptions about the etiology and consequences of CP related to the term "cerebral palsy". In fact, the present results suggest that the term CP may play a role of misinformation on children's understanding about the condition. The term "cerebral palsy" was originally coined when the knowledge of the etiology and pathology of the condition was very limited (Smithers-Sheedy et al., 2013), and the label was based on the external features of the condition (Rosenbaum et al., 2007). The word "palsy" is considered of no use today but was kept because it is a widespread term among professionals of different areas which facilitates communication among the different stakeholders (Rosenbaum et al., 2007). Moreover, school administrators could also consider organizing DAP targeting children and educators (e.g., teachers, parents) to provide clear information about the etiology and its multiple features. Irrespective of the methodology chosen (e.g., infusion-like approach or DAP), conveying knowledge about CP may provide children and educators with robust knowledge, but also, enhance their understanding and acceptance of people with disabilities in school and, hopefully, throughout life. Increasing students, parents, and teachers' awareness about CP is expected to help favor behaviors enhancing the social development of young children (e.g., encourage children with CP to participate in the classroom activities, promote cooperative interactions with their typically developing peers in the playground), and promote their inclusion in the school.

Limitations of the study and future research

The open-ended format question may be an alternative way to surpass the limitations of questionnaires when examining factual knowledge; however, there are also limitations

associated in need to be acknowledged. Students are likely to vary in their interest and writing skill which may have limited the extension and clarity of the responses, and of the final outcome.

Moreover, data collection was conducted with the whole class, which prevented access to each student individually and explore in depth their knowledge and misconceptions on CP. This might help explain the low complexity of some responses and also the high number of responses such as "I don't know". Taking these limitations into account, a semi-structured interview conducted individually could help understand, with further detail, children's ideas.

Furthermore, children indicated whether they knew someone with CP, but this personal experience (e.g., proximity with people with CP, intensity and duration of the experience) was not further checked. Participants' may have considered their experience with diseases with physical impairments similar to those present in CP rather than on the proximity with people with CP (e.g., using a wheelchair to displace themselves in schools may have causes non-related with CP). Future research may wish to control children's level of proximity with people with CP (e.g., intensity and duration of the experience) and further investigate their knowledge about the condition. Findings could inform the design of interventions targeted to favor the inclusion of children with CP in class.

Outubro 2017

References

Act, N. C. L. B. (2001). PL 107-110. *Washington, DC: US Department of Education*.

Almeida, C. F. C. (2012). *A inclusão de crianças com paralisia cerebral no 1º ciclo do ensino regular: práticas educativas inclusivas* (Unpublished doctoral dissertation). Universidade Católica Portuguesa, Viseu.

Altman, B. M. (1981). Studies of attitudes toward the handicapped : The need for a new direction. *Social Problems*, *28*(3), 321–337. doi: 10.1525/sp.1981.28.3.03a00070

Bax, M. C. O. (1964). Terminology and classification of cerebral palsy. *Developmental Medicine and Child Neurology, 6*(3), 295-297. doi: 10.1111/j.1469-8749.1964.tb10791.x

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. doi: 10.1191/1478088706qp063oa

Campbell, J. M., Morton, J. F., Roulston, K., & Barger, B. D. (2011). A descriptive analysis of middle school students' conceptions of autism. *Journal of Developmental and Physical Disabilities*, *23*(5), 377–397. doi: 10.1007/s10882-011-9234-4

Cummings, S. M., Cassie, K. M., Galambos, C., & Wilson, E. (2006). Impact of an infusion model on social work students' aging knowledge, attitudes, and interests. *Journal of Gerontological Social Work*, *47*(3/4), 173–186. doi:10.1300/J083v47n03_11

Fox, C., & Barrett, M. (2008). Children's understanding of mental illness: An exploratory study. *Child: Care, Health and Development*, *34*(1), 10–18. doi:10.1111/j.1365-2214.2007.00783.x

Gigerenzer, G., & Gaissmaier, W. (2011). Heuristic decision making. *Annual Review of Psychology*, *62*, 451–482. doi: 10.1146/annurev-psych-120709-145346

Gillespie-Lynch, K., Brooks, P. J., Someki, F., Obeid, R., Shane-Simpson, C., Kapp, S. K., … Smith, D. S. (2015). Changing College Students' Conceptions of Autism: An Online

Training to Increase Knowledge and Decrease Stigma. *Journal of Autism and Developmental Disorders*, *45*(8), 2553–2566. doi:10.1007/s10803-015-2422-9

Horner, R. H., Carr, E. G., Halle, J., Mcgee, G., Odom, S., & Wolery, M. (2005). The use of single-subject research to identify evidence-based practice in special education. *Council for Exceptional Children*, *71*(2), 165–179. doi: 10.1177/001440290507100203

Ison, N., McIntyre, S., Rothery, S., Smithers-Sheedy, H., Goldsmith, S., Parsonage, S., & Foy, L. (2010). "Just like you": A disability awareness program for children that enhanced knowledge, attitudes and acceptance: pilot study findings. *Developmental Neurorehabilitation, 13*(5), 360-368. doi: 10.3109/17518423.2010.496764

Krahe, B., & Altwasser, C. (2006). Changing negative attitudes towards persons with physical disabilities: An experimental intervention. *Journal of Community & Applied Social Psychology*, *16*, 59–69. doi: 10.1002/casp.849

Ladd, G. W., Kochenderfer, B. J., & Coleman, C. C. (1997). Classroom peer acceptance, friendship, and victimization: Distinct relational systems that contribute uniquely to children's school adjustment? *Child Development*, *68*(6), 1181–1197. doi: 10.1111/j.1467-8624.1997.tb01993.x

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, *33*(1), 159–174. doi: 10.2307/2529310

Lindsay, S., & Mcpherson, A. C. (2012). Strategies for improving disability awareness and social inclusion of children and young people with cerebral palsy. *Child: Care, Health and Development*, *38*(6), 809–816. doi: 10.1111/j.1365-2214.2011.01308.x

Magiati, I., Dockrell, J. E., & Logotheti, A. E. (2002). Young children's understanding of disabilities: the influence of development, context, and cognition. *Applied Developmental Psychology*, *23*, 409–430. doi: 10.1016/S0193-3973(02)00126-0

Martin, H. L., Rowell, M. M., Reid, S. M., Marks, M. K., & Reddihough, D. S. (2005).

Cerebral Palsy: What do medical students know and believe? *Journal of Paediatrics*

and Child Health, 41(1/2), 43-47. doi: 10.1111/j.1440-1754.2005.00534.x

Nadeau, L., & Tessier, R. (2006). Social adjustment of children with cerebral palsy in

mainstream classes: Peer perception. *Developmental Medicine and Child Neurology*,

48, 331–336. doi: 10.1017/S0012162206000739

Nadeau, L., & Tessier, R. (2009). Social adjustment at school: Are children with cerebral

palsy perceived more negatively by their peers than other at-risk children? *Disability*

and Rehabilitation, 31(4), 302-308. doi: 10.1080/09638280801945899

Nangle, D. W., Erdley, C. A., & Gold, J. A. (1996). A reflection on the popularity construct:

The importance of who likes or dislikes a child. *Behavior Therapy*, *27*(3), 337–352.

doi:10.1016/S0005-7894(96)80021-9

Navarro, S. P., & Arechavaleta, B. O. L. (2017). Heuristic reasoning and beliefs on

immigration: An approach to an intercultural education programme. *Intercultural*

Education, *21*(4), 351–364. doi: 10.1080/14675986.2010.506701

Novak, I., Hines, M., Goldsmith, S., & Barclay, R. (2012). Clinical prognostic messages from

a systematic review on cerebral palsy. *Pediatrics, 130*(5), 1285-1312. doi:

10.1542/peds.2012-0924

Odding, E., Roebrock, M. E., & Stam, H. J. (2006). The epidemiology of cerebral palsy:

Incidence, impairments and risk factors. *Disability and Rehabilitation, 28*(4), 183-

191. doi: 10.1080/09638280500158422

Ostensjø, S., Carlberg, E. B., & Vøllestad, N. K. (2004). Motor impairments in young

children with cerebral palsy: Relationship to gross motor function and everyday

activities. *Developmental Medicine and Child Neurology, 46*(9), 580-589. doi:

10.1017/S0012162204000994

Oskoui, M., Coutinho, F., Dykeman, J., Jetté, N., & Pringsheim, T. (2013). An update on the

prevalence of cerebral palsy: A systematic review and meta-analysis. *Developmental*

Medicine & Child Neurology, 55(6), 509-519. doi: 10.1111/dmcn.12080

Parker, J. G., & Asher, S. R. (1993). Friendship and friendship quality in middle childhood:

Links with peer group acceptance and feelings of loneliness and social

dissatisfaction. *Developmental Psychology*, *29*(4), 611–621. doi: 10.1037/0012-

1649.29.4.611

Peters, S. J. (2007). "Education for all?" A historical analysis of international inclusive

education policy and individuals with disabilities. *Journal Of Disability Policy*

Studies, *18*(2), 98–108. doi: 10.1177/10442073070180020601

Rillotta, F., & Nettelbeck, T. E. D. (2007). Effects of an awareness program on attitudes of

students without an intellectual disability towards persons with an intellectual

disability. *Journal of Intelectual & Developmental Disability*, *32*(1), 19–27. doi:

10.1080/13668250701194042

Rosário, P., Hogemann, J., Núnez, J. C., Vallejo, G., Cunha, J., Oliveira, V., … Rodrigues, C.

(2016). Writing week-journals to improve the writing quality of fourth-graders'

compositions. *Reading and Writing, 5*(30), 1009-1032. doi: 10.1007/s11145-016-

9710-4

Rosário P., Núñez J. C., Vallejo G., Cunha J., Azevedo, R., Nunes, A. R., Fuentes, S., &

Moreira, T. (2016). Promoting Gypsy children school engagement: A story-tool

project to enhance self-regulated learning. *Contemporary Educational Psychology,*

47, 84-94. doi: 10.1016/j.cedpsych.2015.11.005

Rosário, P., Lourenço, A., Paiva, O., Núñez, J., González-Pienda, J. & Valle, A. (2012). Self-

efficacy and perceived utility as necessary conditions for self-regulated academic

learning. *Anales de Psicologia, 28*(1), 37-44.

Rosenbaum, P., Paneth, N., Levinton, A., Goldstein, M., Bax, M., Damiano, D., … Jacobsson, B. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology, 109*, 8-14. doi: 10.1111/j.1469-8749.2007.tb12610.x

Sankar, C., & Mundkur, N. (2005). Cerebral palsy-definition, classification, etiology and early diagnosis. *Indian Journal of Pediatrics, 72*(10), 865-868. doi: 10.1007/BF02731117

Schenker, R., Coster, W., & Parush, S. (2005). Participation and activity performance of students with cerebral palsy within the school environment. *Disability and Rehabilitation, 27*(10), 539-552. doi: 10.1080/09638280400018437

Shah, N. (2004). Changing minds at the earliest opportunity. *Psychiatric Bulletin*, *28*, 213–215. doi: 10.1192/pb.28.6.213

Smithers-Sheedy, H., Himmelmann, K., Krageloh-Mann, I., Mcintyre, S., Slee, J., Uldall, P., … Wilson, M. (2013). What constitutes cerebral palsy in the twenty-first century? *Developmental Medicine and Child Neurology*, *5*, 1–6. doi:10.1111/dmcn.12262

Tversky, A., & Kahneman, D. (1974). Judgment under uncertainty: Heuristics and biases. *Science*, *185*(4157), 1124–1131.

Weiss, M. F. (1994). Children's attitudes toward the mentally ill: An eightyear longitudinal follow-up. *Psychological Reports*, *74*, 51–56. doi: 10.2466/pr0.1994.74.1.51

Woolfson, R., Woolfson, L., Mooney, L., & Bryce, D. (2008). Young people's views of mental health education in secondary schools: A scottish study. *Child: Care, Health and Development*, *35*(6), 790–798. doi: 10.1111/j.1365-2214.2008.00901.x

Yude, C., & Goodman, R. (1999). Peer problems of 9- to 11-year-old children with hemiplegia in mainstream schools. Can these be predicted? *Developmental Medicine & Child Neurology*, *41*, 4–8. doi: 10.1111/j.1469-8749.1999.tb00002.x

"WHAT IS CEREBRAL PALSY"

Appendix A

"What is CP?" coding manual.

1. Accuracy of response

    1.1 Correct response

        1.1.1   Correct response with generalization

    1.2 Incorrect response

    1.3 Correct and incorrect response

        1.3.1   Correct and incorrect response with generalization

    1.4 "Do not know"

2. General theme

    2.1 Disease

    2.2 Problem

    2.3 Disability

    2.4 Reference to malfunctioning

    2.5 Other problem or disease

3. Main impairments (motor, posture)

4. Secondary impairments

    4.1 Cognitive impairments

    4.2 Language impairments

    4.3 Sensory impairments

    4.4 Non-specified impairments

5. Etiology

    5.1 Since birth

    5.2 Brain lesion

6. Comments about severity

7. Comments about how people should be treated

Outubro 2017