Universidade do Minho
Escola de Psicologia

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Parenting in Cerebral Palsy: Where and when the challenges and needs occur?

outubro de 2019

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e da
Doutora Armanda Pereira

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STATEMENT OF INTEGRITY

I hereby declare having conducted this academic work with integrity. I confirm that I have not used plagiarism or any form of undue use of information or falsification of results along the process leading to its elaboration.

I further declare that I have fully acknowledged the Code of Ethical Conduct of the University of Minho.

University of Minho, october 18, 2019

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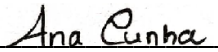
Signature: 

Parentalidade na Paralisia Cerebral: Onde e quando surgem os desafios e as necessidades?

Resumo

A Paralisia Cerebral está referenciada como a desordem física mais comum na infância. É originada por uma lesão cerebral que ocorre em períodos pré-, peri- ou pós-natais, sendo o movimento e a postura as áreas mais comumente afetadas. O exercício da parentalidade com uma criança com estas características traz desafios e também necessidades acrescidas, por exemplo, necessidades de informação. O objetivo do presente estudo foi o de identificar os desafios e necessidades parentais percebidos por pais de crianças com paralisia cerebral que frequentam o primeiro ciclo do ensino básico. Para tal foi usado um desenho qualitativo, no qual os 11 participantes responderam a uma entrevista semiestruturada centrada na sua experiência de educar uma criança com uma esta perturbação desenvolvimental. As entrevistas foram analisadas segundo uma abordagem temática e recorrendo ao *software Nvivo*. Surgiram então quatro temas: (1) Desafios experienciados pelos pais, (2) Necessidades parentais de informação, (3) Necessidades parentais de suporte e, (4) Necessidades parentais de bem-estar pessoal. Foi ainda possível identificar o(s) contexto(s) e o(s) período(s) de desenvolvimento em que os desafios e as necessidades ocorrem. É expectável que estes resultados possam contribuir para o desenho de intervenções e o estabelecimento de boas práticas junto desta população.

Palavras-chave: desafios, necessidades, paralisia cerebral, parentalidade

Parenting in Cerebral Palsy: Where and when the challenges and needs occur?

Abstract

Cerebral Palsy is considered the most common physical disorder in childhood. It is a neurodevelopmental disorder, caused by a brain injury that occurs in pre, post or natal periods with movement and posture impact. Parenting a child with these clinical features brings challenges such as additional parenting tasks and also requires, for example, the need for further educational information. The present study aimed to identify the parenting challenges and needs faced by parents of children with cerebral palsy attending elementary school. For this, a qualitative approach was used with a sample of 11 participants who responded to a semi-structured interview centered on their experience of educating a child with Cerebral Palsy. The interviews were analyzed according to a thematic analysis approach. Four themes were identified: (1) Challenges experienced by parents, (2) Parental need for information, (3) Parental need for support, and (4) Parental need for personal well-being. It was also possible to identify the context(s) and period(s) of the children's development in which these challenges and associated needs occur. Findings are expected to contribute to identify good practices and benefit the parenting experience of parents of children with cerebral palsy.

Keywords: cerebral palsy, challenges, needs, parenting

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Parenting in Cerebral Palsy: Where and when the challenges and needs occur?

Cerebral Palsy (CP) comprises a group of neurodevelopmental disorders that affects mostly movement and posture (Rosenbaum et al., 2007). This condition is caused by an early brain injury and may occur during pre-, peri-, or postnatal periods (Bax et al., 2005; Rosenbaum, 2003; Rosenbaum et al., 2007). In Europe, CP prevalence is 1.5 to 2.5 children per 1000 live births (Surveillance of Cerebral Palsy in Europe, 2002), and worldwide about 17 million people live with this disability (Australian Cerebral Palsy Register Group, 2013). CP is a disorder stable in time, non-progressive with lifelong impact. Moreover, CP is considered the most common childhood physical disorder (Aisen et al., 2011; Bax et al., 2005; Kurt, 2016; Novak et al., 2013). The severity and type of dysfunction experienced by children with CP depends on the size, type, and location of the brain injury. The brain injury characteristics have an impact in the nature of motor impairment and muscle tone type, and, consequently, in the autonomy level experienced by children with CP (Graham et al., 2016; Krigger, 2006; Rosenbaum et al., 2007). Therefore, CP motor impairment features could be classified according to the topography of the lesion and muscle tonus quality (Aisen et al., 2011; Bax et al., 2005;). Regarding the former, CP may be dichotomized into unilateral (only one side of the body is affected) or bilateral (two sides of the body are affected). The unilateral classification comprises monoplegia (i.e., one limb affected, more often, the lower limb) and hemiplegia (i.e., upper and lower limb affected); while the bilateral classification comprises diplegia (i.e., all limbs are affected, lower with more severity), triplegia (i.e., upper and lower limbs affected in the same side of the body, and a third limb affected in the other side of the body) and quadriplegia (i.e., the four limbs and trunk are affected) (Graham et al., 2016). Finally, the muscle tonus quality classification comprises four types: (1) dyskinetic (i.e., uncontrolled and writhing movements); (2) ataxic (i.e., difficulties in coordination and balance); (3) spastic (i.e., increased muscle tone); and (4) mixed (Aisen et al.,2011; Gorter et al., 2004;). The brain injury impact frequently has an extended effect in the intellectual and/or sensorial impairments (Johnson, 2002). Therefore, some comorbidities such as epilepsy, communication, auditory, and visual impairments could be associated to this clinical picture (Carr, 2005). For example, depending on the severity of motor (e.g., primary) and secondary impairments, children with CP could show limitations in self-care (Raina et al., 2005).

In sum, CP is a broad clinical condition providing a large heterogeneity in the impairment profile, i.e., two people with CP, rarely show the exactly same impairments profile (Rosenbaum, 2003). To cope with these clinical features, parents face a set of challenges while educating a child with CP. These challenges begin with the diagnosis moment and continue through their life (e.g., the long-term

dependency and the need for special care services) (Mendenhall & Mount, 2011; Rosenbaum, 2003). There is limited investigation focused on the challenges and needs to cope with these challenges faced by the parents of children with CP (e.g., promote the autonomy of a child with CP with a limited mobility), and on which timings and contexts both occur (e.g., how to care of the new born child with CP at home after hospital discharge?). Findings are expected to help researchers and practitioners further understand the nature of these challenges and help parents better cope with them.

Parenting experiences in CP: Challenges and needs mapping

Whittingham, Wee, and Boyd (2011), investigated the parenting challenges in raising children with CP through a focus group with parents and health professionals with expertise in CP intervention. Findings allowed the identification of a set of parental challenges as follows: grief dealing (i.e., diagnosis and changes in the expectations), additional parenting tasks (e.g., help in the mobility) and parenting under public scrutiny (i.e., stigma perception). Moreover, parental needs to cope with their children with CP have also been studied over the past few years. For example, Palisano et al. (2010) study has shown that more than 50% of the participants (501 parents of children and youth with CP), reported needs for information (e.g., planning the future) and the need to have time to themselves. In other study, Buran, Sawin, Grayson, and Criss (2009) found that the needs for services (e.g., recreational/entertainment) are the most reported by parents, followed by the needs for information (e.g., planning the future of the child).

Recently, Dieleman, van Vlanderen, Prinzie, and De Pauw (2019), conducted a research aiming a depth understanding of the parental experiences in the process of taking care of adolescents with CP. Grounded in the Self-Determination theoretical framework (Deci & Ryan, 2000), these authors analyzed parents basic psychological needs (i.e., need for autonomy, relatedness, and competences). Findings indicate that parents reported to face challenges related with the need for autonomy (e.g., at least one of the parents is unlikely to fully satisfies his/her professional goals), need for relatedness (e.g., decline an invitation to participate in a social activity which is not adapted to their child) and need for competence (e.g., difficulties to help her/his child accept her/his disability). Moreover, Dieleman et al. (2019) also reported that parents of children with CP are likely to experience difficulties in accepting the diagnosis and deal with the uncertainty about the child future. This finding is consistent with the work by Cheshire, Barlow, and Powell (2010) which found that parents of children with CP when compared with parents of children typically developed show poorer psychological well-being (e.g., lower satisfaction with life, and higher levels of anxiety and depression).

All considered, prior research mapped the challenges and needs faced by parents of children with CP independently. However, and to the best of our knowledge, there is limited investigation on the

challenge(s) in association with specific need(s), and no studies provided data regarding the developmental period, and social context, in which the challenges in association with the needs occur more frequently. Further investigation is needed to understand the challenges and needs faced by the parents of children with CP; findings are expected to deep further researchers and practitioners understanding of the timing (when) and context (where) in which these parents need support.

To achieve this purpose, the current study is informed by two bodies of literature: (a) Critical Developmental Periods, and (b) Bronfenbrenner Ecological Systems Theory. These two theoretical bodies of knowledge helps address the challenges and needs in relation with the timing and context in which they occur.

Critical Developmental Periods approach

Across the life-span development of individuals with CP, each stage of development is characterized by specificities consistent with the severity of the clinical picture (Rosenbaum, 2003). These distinct behavioral, emotional and cognitive challenges feed the individual rehabilitation goals and the rehabilitation plan set to promote autonomy in these children (Trabacca, Vespino, Di Liddo & Russo, 2016).

Besides, children with CP show distinct behavioral, emotional and cognitive impairments according to their stage of development and period of life (e.g., first day in elementary school), and parents are expected to be are able to provide responsive support to their children needs every time. This social expectation is likely to display parents anxiety which could impact negatively in their parents self-efficacy (Trabacca et al., 2016).

Since birth, parents of children with CP struggle with the comparation of their children developmental milestones achievements with those of children with typical development in the same period of growing (e.g., walk in the infant/pre-school period). Moreover, one of the most important transitions period in the life of a child and his/her family is the beginning of the formal education (Niesel & Griebel, 2007). Prior research termed this transition as “universal social stressor” or a “normative stressor” due to the changes expected in peer-group relationships and the need to respond to social and cognitive requirements (Groeneveld et al., 2013; Rimm-Kaufman & Pianta, 2000; Russ et al., 2012). Moreover, school is considered one of the major interaction systems that parents have to manage while educating a child. In the specific case of children with a developmental disorder this period assumed an additional stressful factor for parents and children (Dockett & Perry, 2007

Bronfenbrenner Ecological Systems Theory

According to Bronfenbrenner (1977), understanding human development is a complex process that "requires examination of multiperson systems of interaction not limited to a single setting and must take into account aspects of the environment beyond the immediate situation containing the subject" (p.514). This theoretical framework helps to understand the interconnections between people and environment (Hepworth, Rooney, Rooney, Strom-Gottfried, & Larsen, 2013) by suggesting four levels of analyses: micro-, meso-, exo- and macro-systems (Bronfenbrenner, 1977). The micro-system refers to interactions between one or more individuals and the environment (e.g., parent, teacher). In this level, for example, parenting practices and parent-child interaction have an important role in the process of educating a child with a disability (Algood, Harris, & Hong, 2013). Meso-system encompasses relationships and connections between two or more micro-systems (Bronfenbrenner, 1977). The interrelations between these two micro-systems create a meso-system (e.g., relationships within a family - the caregiver's marital relationship (micro-system) is expected to influence the parent-child relationship (micro-system). which impacts on children life (Algood et al., 2013). Exo-system is an extension of the meso-system and includes the major institutions of the society (e.g., Mass media, agencies of the government). Macro-system comprises the values, laws, and cultural mores that frame individual life's (i.e., culture); this level of analysis is likely to influence the other three systems of the model (Bronfenbrenner, 1977). For example, the health care delivery system is particularly relevant for parenting a child with a disability (Algood, et al., 2013). For the purpose of this study, only three of the four systems were explored (micro-, meso-, and macro-systems).

All considered, the current study aims to identify the parenting challenges and associated needs faced by parents of children with CP attending elementary school level.

We believe that investigating these features in relation with the timing and the context where these challenges and associated needs occur will further our understanding about the parenting of a child with CP. Moreover, these findings are expected to contribute to develop interventions aimed to support and promote parental competences, enhancing the quality of life of families with children with CP.

Materials and Methods

Participants and recruitment process

To participate in this study parents should have at least one child: (i) with a diagnose of CP, and (ii) enrolled in the elementary school level. The recruitment process took place at two CP rehabilitation centres of northern Portugal, between November 2018 and January 2019. The purpose of this study and the procedure protocol were fully explained to the rehabilitation center staff. During the rehabilitation

sessions, therapists contacted with eligible parents and invited them participate in the study. Parents who agreed to participate, were posteriorly contacted by the research team and were presented the purposes of the study in-person. Participants authorized researchers to consult their children medical report to collect detailed information about the specificities of the diagnosis. The confidentiality and anonymity of the data were guaranteed. Finally, participants read and signed the "Free and Informed Consent", and scheduled the interview.

A total of nine mothers and two fathers *(N = 11)* participated in the study. Parent age range was between 25 and 49 years (*M* = 39.50, *SD* = 6.06). One of the mothers has two children (twins) that fitted the inclusion criteria. Regarding educational attending, more than 50% of the participants had completed high school or college. All participants have more than one child with exception of three parents (Table 1). Regarding children sociodemographic information, three are female and nine are male (*N* = 12), with ages ranging between seven and 10 years old (*M* = 9.08, *SD* = 1.50). All the 12 children were attending a mainstream public school. Seven of them were enrolled with special education curricula inserted in a regular class and five of them were attending a multi-disability unit (Table 2).

Table 1

Demographic characteristics of participants: parents (N = 11)

Participants Characteristics – Parents of Children with CP		
	N (%)	*M* ± *SD*
Age (years)		39.50 ± 6.06
Gender		
Male	2 (18.2%)	
Female	9 (81.8%)	
Educational level		
Elementary School	2 (18.1%)	
Middle School	2 (18.1%)	
High School	5 (45.5%)	
Higher Education	2 (18.1%)	
Number of children		
One	3 (27.3 %)	
Two	4 (36.4%)	
Three or more	4 (36.4%)	

Table 2

Demographic characteristics participants' children (N=12)

Participants' children characteristics		
	N (%)	*M* ± *SD*
Age (years)		9.08 ± 1.50
Gender		
Male	9 (75%)	
Female	3 (25%)	
Type of CP [n (%)]		
Tetraparesis	6 (50%)	
Right hemiplegia	1 (8.3%)	
Without classification	5 (41.7%)	
Quality of Tonus [n (%)]		
Spastic	6 (50%)	
Without classification	6 (50%)	
Comorbidities		
DiGeorge Syndrome	1 (8.3%)	
West Syndrome	1 (8.3%)	
GMFCS		
Level I	2 (16.7%)	
Level II	3 (25%)	
Level III	1 (8.3%)	
Level IV	2 (16.7%)	
Level V	4 (33.3%)	

Procedure

The study was guided by the following research question: Understand the parenting experience of parents of children with CP attending the elementary school level. To address this question, a qualitative Approach was used and all participants responded to a semi-structured interview.

Data collection. The data collection design followed three phases: (i) prior to interview, information about the children clinical condition was asked to therapist and parents; (ii) just before the interview an educational video was present to parents; finally, (iii) participants were interviewed.

Firstly, the children Gross Motor Function Classification System (GMFCS) level was requested to the physical therapists. GMFCS is a standardized classification system that classifies the gross motor children's skills (e.g., walking, climbing stairs, sit) in one of the five descriptive levels considering the motor severity (level I to V). This is a reliable classification instrument for children with CP (intraclass correlation coefficient .95, 95% CI .90-.97) (Palisano et al., 1997). Additionally, parents were asked to fulfill a sociodemographic questionnaire (e.g., literacy level, number of children).

Educational Video. Afterwards parents were invited to visualize a five minutes educational video before the interview moment. The educational video (Diu & Lockhart, 2015; see https://s.telegraph.co.uk/graphics/projects/fathers-days/index.html) was created by a cartoonist from the Telegraph "whose experience of fatherhood was unlike anything he had expected". The video was translated to Portuguese in audio and using subtitles. The video presents, in two different parts, a self-report of the expectations, difficulties, and adaptations to the fatherhood of a child diagnosed with CP. Firstly, the video explored the diagnosis communication reaction, highlighting father's perception of loss of control and lack of information about what was happening. The second part explored the management and adjustment of the parenthood expectations to the long-term health condition of his daughter (e.g., acceptance, guilt feelings, setting priorities).

This video was used with an ice-breaker purpose. The option of using this method were grounded on the fact that parents of children with CP are frequently questioned about developmental goals regarding their children and difficulties in the process. Consequently, their narrative is likely to develop a practical and goal-driven approach. Through the presentation of a peer experience we aimed to promote an emotional connection with characters (e.g., Singhal & Rogers, 2002) and instigate participants readiness to reflect on the challenges and needs in their parenting of CP children.

The rationale to use the video was theoretically rooted on the model by Larkey and Hecht (2010). These authors conceptualized a theoretical model (Narrative as Culture – Centric Health Promotion) to describe the relationships between the narrative and their effects on health behaviors. This model has three levels: the narrative characteristics, the mediators and the outcomes/responses that sequentially affect each other (Larkey & Hecht, 2010). The first one is related to the involvement of the person exposed to the narrative with the characters, the story and the cultural aspects associated. To this aim, story and characters must be realistic.

The main persuasive effects identified by this model are emotional connection (i.e., empathy and linking) and the identification with the characters (Singhal & Rogers, 2002; Slater, Rouner, & Long, 2006). Moreover, the mediator (narrator) promotes the process of understanding the phenomena by engaging

people who is watching the video to the story in a personal level. These first two levels are expected to predict positive attitudes towards, and, in some cases, behavior changes. The last one, outcomes/responses level, is related to the transfer of the lessons learned on the narrative to the real world. The identification with topics in the story is expected to trigger actions in the individual life (e.g., discussion) (Larkey & Hecht, 2010).

The video used in this study fitted in the narrative characteristics mentioned in the model as follows: realistic (a nearby story), emotional connection, and identification with the characters ("that person is like me") (Larkey & Hecht, 2010).

Semi-structure interview: After the visualization of the video, parents participated in a semi-structured interview focused on their perceptions of parenting challenges and major needs faced while educating a child with CP. This qualitative data collection method uses open-ended questions to promote detailed storytelling sharing about participants own perception (Madill, 2012). The data collection took place in a sound-proof room (medical office) in the rehabilitation centre.

The six open-ended questions of the interview aimed to: (i) explore the participants' feelings and thoughts while watching the educational video (e.g., How do you felt watching this video? What do you think about the message conveyed?) and (ii) learn their thoughts about being parent of a child with a developmental disorder (e.g., If I ask you about what is like be a father of a child with a developmental disorder, what would you say?).

All the interviews were audio recorded and then transcribed verbatim.

Data Analysis

To analyze the interviews we used the thematic analysis approach (see Braun & Clarke, 2006). After the identification of the codes through "top-down" and "bottow-up" analysis, researchers searched for patterns and interconnections between codes to generate themes (Braun & Clarke, 2006).

Prior to the analysis, a coding frame (codebook) was created based on the theoretical background (e.g., Buran et al, 2009; Dieleman et al., 2019; Palisano et al., 2010; Nurullah, 2013) and on the two bodies of knowledge selected to ground this research. Specifically, for the critical developmental periods the codes were retrieved from the theory and matched with the participant's speech (i.e., Pre-natal; Birth and Neo days; First days at home; Pre-school period; School period; and Life-span). Moreover, a deductive approach was used to code the data, fitting data to these theoretical-driven codes. During the process, news codes emerged from the data.

Data analyses were conducted with the assistance of QSR International's NVivo 10 software. This software simplifies the data analytics and provides tolls for and support in the search process of map interconnections between codes and check for patterns (Bazeley & Jackson, 2013).

The codification of the data involved two researchers (AC and AP) with training on qualitative analysis. AC codified all the data and AP codified 30% of the data. Consensus was reached after discussing the discrepancies in the codification. The inter-observer agreement reached (κ=.90) indicates an almost perfect agreement according to Landis and Koch (1977).

Results

Data were organized and reported against the two bodies of knowledge considered, i.e., in which development period challenge and need is more prevalent and in which context occurred more frequently. Using a thematic approach four themes emerged: (1) Challenges experienced by parents, (2) Parental needs for information, (3) Parental need for support and, (4) Parental need for personal well-being. Categories were screened using the criteria of Hill et al. (2005) to Consensual Qualitative Research (CQR), i.e., general, typical and variant outcomes. A general outcome means the theme is present in responses from almost all the participants (i.e., 11 [91.6%] or 12 [100%]). This type of outcome suggests that these findings match the speech of the majority of the participants. A typical outcome includes more than half of the sample until the cutoff for general. In this case means the theme is identified in responses from at least seven (58.3%) but no more than 10 (83.3%) of the 12 participants. Lastly, a variant outcome comprises at least two cases up to the cutoff for typical. In this case means the theme is present in responses between two (16.7%) and six (50%) of the 12 participants (see Table 3).

This section presents the general and typical findings by theme.

In the reported findings, participants verbatim quotes were introduced to illustrated categories patterns that were identified in the conversation held during the interview.

Theme 1: Challenges experienced by parents

Most of the participants reported challenges that they had experienced some years ago (shortly after the birth of their child with CP), were facing at the moment, or were anticipating that they would facing in the future. Regarding the birth and neonatology experience, participants highlighted diagnosis acceptation as a relevant step stone of the process. Participants reported to have felt anger, guilty and sense of unfairness in the diagnosis moment. However, most of them were able of overcome these feelings and accept their child condition. *"At home A. is now fully accepted; but when you learn the diagnosis* [...]*, in that moment is difficult to accept the situation* [...] *is not easy, because it is a shock"* (A1p0).

Table 3

General, Typical and Variant Outcomes from the Cross-Analysis of 12 parents' interviews

Theme	*General Subtheme(s)*	*f*	*Typical Subtheme(s)*	*f*	*Variant Subtheme(s)*	*f*
Challenges experienced by parents	Additional daily parenting tasks	12/12	Achievements	10/12	Anticipation with the transition to the adulthood	6/12
	Comparison with typically developing children	12/12	Comprehension of children functionality	10/12	Parents' physical health	5/12
	Diagnose acceptation	12/12	Family management	10/12	Job and childcare management	4/12
	Parenting burden	12/12	Comparison with non-typically developing children	8/12	Parental social isolation solation	3/12
	Parents' mental health	11/12	Social Stigma	8/12		
Parental needs for information	Lifespan	11/12	Meso-system	10/12		
			Micro-system	10/12		
			Macro-system	7/12		
Parental needs for support	Lifespan	12/12	Birth and Neo days	10/12	First days at home	5/12
	Meso-system	12/12				
Parental needs for personal well-being			Lifespan	10/12		
			Micro-system	10/12		
Parental needs for services					Lifespan	5/12
					Meso-system	5/12
					Macro-system	5/12

Following to the diagnosis moment, a set of not expected parenting tasks occupied family time requiring a strict time-management (e.g., medical consultations, therapies) *"*[...] *was born on June 23rd and went home on July 7th. Until July 29th we* [my son and I] *attended a total of 37 consultations with different therapists and medical doctors* [...]*"* (A1p0), and the need to set priorities to ensure that the needs of the new born child with CP were fulfilled "[...] *My husband agreed with me that I needed to quit my job. We agreed that I stay in home taking care of our daughter and doing everything for her benefit, rather than earning money of having a career*" (M1e0).

Consequently, parents reported the need to be engaged in a continuous learning process on how children with CP behave, on their needs and understand how they could establish safe routines for their children. Despite acknowledging the complexity of the ongoing educational challenge, parents stressed this process as positive and rewarding *"Despite the huge efforts G. makes to talk better, he cannot hold a clear and completely understandable communication. So, to communicate with him, sometimes we have guess his possible needs or wishes. We have to think on things that we anticipate that he is going to ask. We have to put ourselves in his shoes and find the word that he wants to say, and that works for him and for us"* (G8I1).

Children small achievements become relevant because after the diagnosis of long-term health condition, parent's expectations about their children abilities are limited. For that reason, all the child achievements are considered very important hallmarks for the family hope increasing. *"*[...] *G. teaches us that* [...] *he never gives up. We did not expect that he would walk, and today he walks; G. was not expected to succeed in school, but he attends school and has good grades"* (G1p9).

However, parents of children with CP reported that is unavoidable to compare their children behaviors with those of children with typical development; but they mentioned to feel displeasure when they listen to comparisons regarding their own children made by others. Furthermore, this social judgment is often associated with lack of knowledge about the clinical condition and is likely to cause suffering and anger for parents of children with CP *"One time, my daughter was yelling at the supermarket and one lady covered the ears of his son. This child told her that he wants to yell too, but the mother replied: "Son, you are not a freak". This sentence hurt me deeply"* (B8e6).

Educating a child with CP was associated by parents to a constant feeling of pressure or burden and, in some moments, to disturbance in their mental health state *"we always feel an agony, me and my wife, that pushes us to learn more to be able to teach G. everything that may help him feel normal and live a happy life"* (G1p9); *"There were days that I just wished to disappear. That days still exist"* (B8e6).

Some of the challenges reported by parents are related to specific needs. This relation will be addressed in the following sections considering the developmental period and the context (micro-, meso-, macro-system) in which the reported behavior occurred with higher frequency.

Theme 2: Parental need for information

Parents reported that during the journey of educating a child with CP they often felt the need for more information about the clinical condition. All participants had premature children with CP and the diagnosis communication was reported as a relevant steppingstone to the task of parenting their child. Participants stressed that the birth of a premature child with a clinical diagnosis unleashes a mix of emotions, thoughts, and questions that were difficult to deal with. For example, surprise, doubts about the disability in itself, uncertainty about the prognostics, fear about the future, doubts about their ability to educate a child with a long term health condition and general questions about the process, such as "why did this has happened to my child?" (M1e0), "why this happened to us?" (L6l8). These questions have a different nature: those mostly about the reasons why their child had born with CP, and, the others about daily life management (e.g., what to do? how can we promote his/her autonomy? what to expect?). The latter increase the need for information to help parents cope with educating a child with CP. The need for information was referred by participants as something that is always present in their lives due to the fact that CP is a long-term health condition with a lifelong impact. *"In the beginning, everything was scary, I didn't know what was going to happen, I didn't understand anything, I didn't know the purposes and how to use some medical devices* [...]*, but today we have more knowledge about the process, we feel a little less threatened* [...]*"* (B1s6).

Parents stressed the rehabilitation process as an example of a set of medical appointments, sessions with rehabilitation therapists and activities that occupies an important part of the family days. They all mentioned that CP is complex and unique due to the distinct manifestations of the clinical condition for each child, and for that reason they often lack information about what and why to follow the protocols indicated by the medical doctors or the rehabilitation therapists. For example, participants reported the difficulties felt to understand and accept that a child with 15th days of life is in need of being submitted to physiotherapy treatments. *"I didn't know what was the main purpose of occupational therapy* [...] *the physiotherapy purpose was more clear* [...] *useful for the neck pains. Well, at home I did what I could, I used to put a warm towel on the back and giver a massage, and that was it [laughs]. But the neurological rehabilitation is very different, that is something don't you agree?"* (A1p0).

Notwithstanding, parents stressed that the rehabilitation therapists working with their children were available and prepared to explain the specificities of therapy and the benefits associated. Parents

reported seizing the availability of these therapists to teach them some techniques that they could use at home to improve their child competencies and autonomy. Another topic found in this theme was related with the planning of a new pregnancy. One of the participant mothers shared that she wanted deeply to plan another pregnancy; however, she was afraid about the possibility of having another child with CP. A participant father who had other child after the first with CP, reported that this latter pregnancy entailed high tension for all the family; during the pregnancy both parents felt in a permanent alert mood which led them to monitor the process closely with several medical doctors to ensure that the baby was growing as expected. *"For example, thinking in having another child It is difficult, because we need to overcome the barrier of the first experience. I would like to have another child, but obviously, there is some pain and bruises associated, you understand what I mean* [...] *when I give this idea some thought. Because,* [...] *how can I put it? This was a relevant learning experience for my life, but I don't want to repeat it"* (T7f4).

Moreover, parents also stated that services and organizations their children were attending (e.g. social services, hospitals) need to learn further about this disability to better understand the unique nature of CP and the problems associated with the condition. Parents identified key-persons that should improve their knowledge about CP: extended family, friends, and doctors. About the last ones, a mother referred that the specialist doctors tend to have sensibility to the specificities of this disability, but general practitioners no (e.g., emergency doctors). *"*[...] *a simple example: the respect for people with this clinical condition and their families. Children with CP are likely to have a weakened respiratory system, and because of that, when we are in the hospital, we can't be in the waiting room for a long time, where there are countless bacteria's. So, I always inform the nurses that my son has bronchopulmonary dysplasia, and ask them to put us in another room so we can wait without being so exposed* [...]*. Most of the doctors understand and try to find a room, but other tell me that we have to wait there as all people, and that solution often comes with a respiratory infection and a stay of a few days in the pediatric hospital* [...]*"* (V1m7/P1m7).

School is also referred as a context in which educators (e.g., school administrators, teachers, staff) show lack of information about CP. As an example, parents mentioned the typical food meal offered in schools to children with CP with feeding impairments not fitted to their needs. One participant mother referred that school did not prepare the food for her daughter following the medical doctors recommendations, and because of that, her daughter was losing weight. As this situation was recurrent despite the alerts to the school administration, the family decided to prepare the food at home. *"The soup has to be chopped very well, neither too thin nor too thick. At school, the soup it would stick on the wall,*

as students say. M. can't swallow that it and almost all the soup in the spoon stay outside her mouth rather than inside. The truth is that her weight was decreasing, despite the supplement cans [...] *the school is not helping as expected. So, we decided to add the task of preparing her meals to the never ending list of tasks for every day* [...] *"* (M1e0).

Parents also reported that "society as a whole" does not cope well with children with disabilities. To exemplify, participants said that people are not likely to be aware of the load involved in educating a child with CP. Furthermore, parents stated that for example, either in school or in the hospital children with CP face a strong challenge: "the stigma of being different". According to participants, the majority of the stigma situations occur due to lack of information about this clinical condition. Parents stressed that people with more awareness about disabilities are more available to deal with their children differently. For example, some children with CP struggle to find other children available to play in the playground or adults open to listen without judging. *"When we are in a coffee shop or in the restaurant, my son always wants to place the order. He looked me in the eyes and asks gently "Mom, can I go?"; now I encourage him to "Go on, son. Go and order the sandwich". Now, I let him do it. But for a long time I protected him because I knew that people would look at him like an alien. Sometimes people say horrible things in a mumble. We don't have a society ready for these kids"* (A1p0).

Theme 3: Parental need for support

The need for support was identify as a general theme in the parents speech. More specifically, parents reported the need for being supported but, also, the need for giving support.

Participants mentioned the day of the birth and the days at the neonatology sector at the hospital as the most stressful moments. During this time frame parents received their child diagnosis and, consequently, reported the emergent need for being supported at that moment. Most of participants stressed the relevance of having access, for example, to the support from an educator with proper training to help them cope with the diagnosis and answer their questions about how it will be their daily life. *"*[...] *when your first born son has CP, the situation is even more difficult because you feel completely lost: It is our first experience* [...] *to the expected inexperience of a rookie, you add the absolute sense of being alone with a huge task ahead. You hear multiple tips, suggestions, warnings and advices from different people in different places; several inconsistent, most wrong. And you feel alone, you don't know where you should go or who can help you* [...] *when they [medical doctors at the hospital] give you the diagnosis of long term health condition there should be someone, not necessarily a medical doctor, an educator with medical training, or a parent with a child with CP giving you support and* [...] *hope*" (S7c8).

Contrarily to the majority of participants in this study, a mother of twins with CP reported that enrolling in the neonatology support group did not help her. When compared with the other parents in the support group with children with CP, this mother perceived her situation as very distinct and unique. For this reason, instead of receiving support from the group, she felt even more uncomfortable and anxious than she was before enrolling the group. *"*[...] *I quit attending the meetings* [support sessions for parents of children held by a hospital] *because there I found parents whose children with CP were in the neonatology for 15 days while my sons were hospitalized for more than six months. For me, that sessions didn't make much sense because I didn't have anything to add, I didn't want to talk there about my parenting experience because it is bad"* (V1m7/P1m7).

However, this particular experience was not representative of the general discourse of participants regarding the importance of sharing and learning from peers with similar experience. The majority of participants reported talking with parents of older children with CP (e.g., in the waiting room of the rehabilitation center) in the first months after their child was born as a positive experience. These parents understood these conversations as opportunities to collect information and benefit from peers-support; participants mentioned that parents with more experience helped them better understand new possibilities and alternative paths to design their family routines. *"I learned very much in the waiting rooms; sometimes more important things than those learned in the therapies"* (A1p0).

Beyond this support (focused on encouraging the acceptance of the diagnosis), some participants reported the need of support on how to perform the daily parenting tasks with their child. They also stressed the need for support from a formal caregiver that could take care of their child for some time. This help would allow parents to have time for themselves (e.g., go to the medical doctor, rest in the coach). *"How is to be mom of B.? How can I say* [about myself]*, B. occupies much of my time.* [...] *I don't have plenty time for my things: to go to a hairdresser* [...]*; For example, unfortunately, I didn't do medical exams for a long time; and because of that delay, now I have to do a surgery. To take care of B, we do not take care of ourselves* [...] *"* (B1s6).

Some participants reported the need for support other parents that are in the beginning of the process of taking care of a child with CP. One father shared an experience in a support meeting to illustrate how parents in the first months may feel confused and anxious. *"*[...] *I remember one time in one support meeting there was a couple with a child, a baby, a newborn baby; so, they had learned recently the diagnosis and they questioned out loud: "What will happen with our life?". In these meetings it is important to transmit that the world does not finish with the diagnosis of CP, everything is possible; of course, it depends whether they are willing to believe it or not"* (G1p9).

Parent's reported that this need for support and help to care for their children will be present for the rest of their lives. However, the days at the neonatology and the moment of the diagnosis communication could be considered a critical period to benefit from support.

Theme 4: Parental need for personal well-being

The majority of participants reported needs related to their own well-being. While accompany their children education, parents mentioned to follow strict routines with many and very diverse physical and emotional demanding tasks likely to cause stress and fatigue (e.g., children with CP unable to walk need to be picked up by their parents/caregivers for every displacement). *"We don't have any relaxing moment because we are always alert to learn if one of them is drooling to clean him; if V. have pee or if P. wants to poop. So, I think that for us there is no moment of rest and quiet peace* [...] *We are always busy"* (P1m7/V1m7).

Occasionally, participants reported to feel the need to renounce to do something pleasant for themselves to take care of the child. *"Many times, I desire want to watch or play football with my friends, but I know that if I stay at home with my son he will be happy and safe. So, I stay."* (G8I1)

Some parents mentioned that their children will need to be taken care of in a life-long term. This fact requires reflection about the expectations and challenges associated. For example, participants reported the constant need to manage the physical and emotional fatigue. "[...] *Sometimes, at the end of the day, my head is completely exhausted. I´m always very tired. I go to bed early, like 11 p.m., because I´m tired and I need to rest to have strength to cope with all my tasks, but I can't sleep. My personal doctor gave me a medicine, but for now I don't want to create an addition to the pills"*. (M1e0)

Additionally, parents reported to feel demoralized when realizing that despite their daily efforts, the goals set for their children health are not being accomplished as they hoped. Some parents mentioned that they fight on a daily basis with their-own reality, because they believe that with a strong commitment and effort, their children lives would improve (e.g., begin walking, be independent). However, in some cases, the children health evolutions are not consistent with the efforts displayed. Some parents mentioned that their own well-being is threatened when they realize the slowness of the improvement process, and the limited level of control on the results of their efforts. *"*[...] *During many years this was my daily fight: do everything for him, every effort to help him be capable of walk independently. But now I begin to realize that is being hard to reach this goal* [...] *despite all the therapies* [...] *it's being much more difficult than what we had anticipated and idealized for him all these years."* (G8a9).

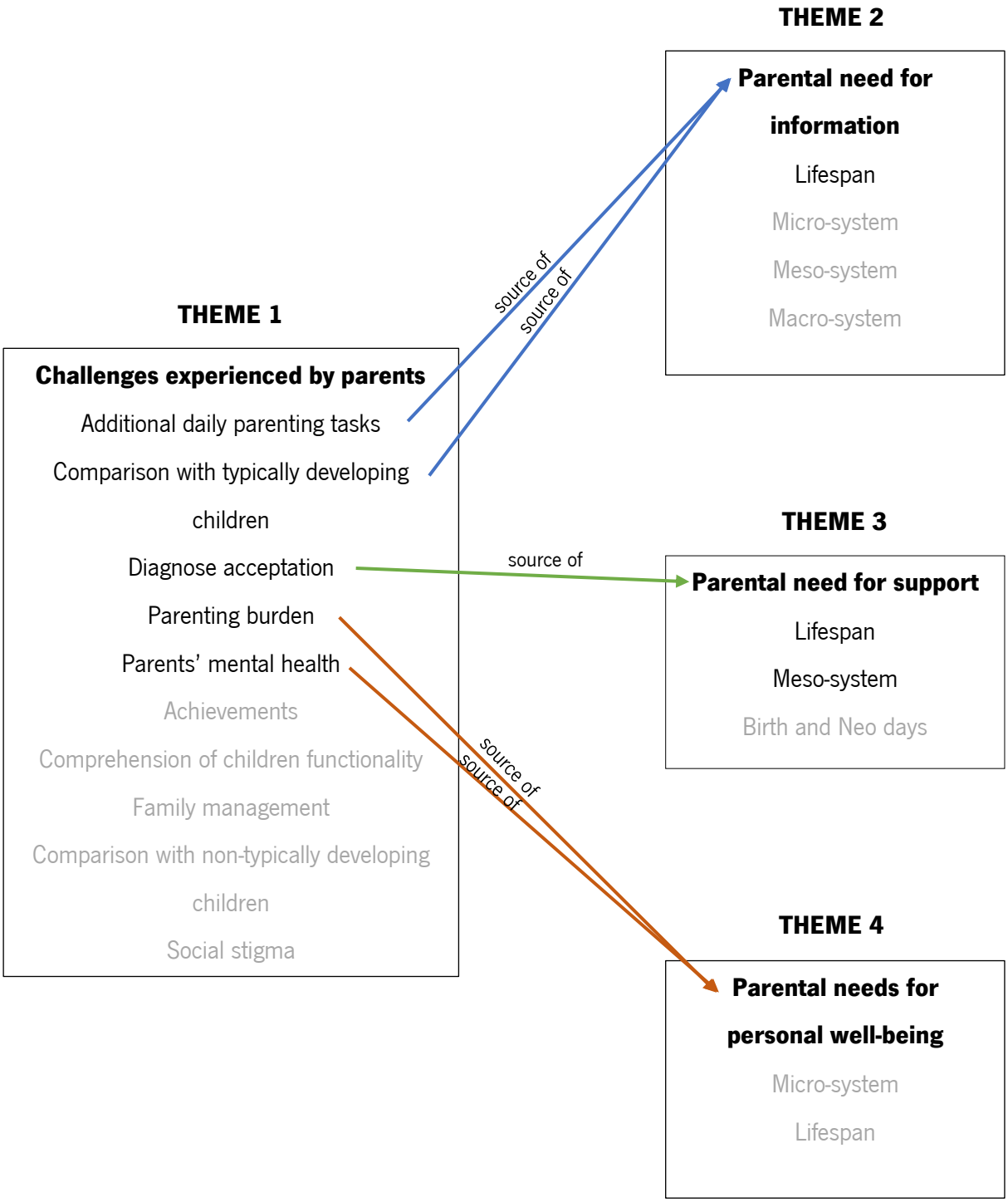

Figure 1. Themes, sub-themes and the connections between them. In black the general and in grey the typical sub-themes

Discussion

In Europe, about 5, 075 million children born every year (Eurostat, 2017). However, between seven and 13 thousand children are diagnosed with CP. A deep understanding of the experiences lived by parents could be crucial to improve the quality of life of families with children with CP.

To increase participants predisposition to talk about their parenting experience, prior to the interview, they were invited to visualize an education video in which a father of a child with CP reports his own story through comics. All participants report an identification with the story *"It looks like I was watching the story of my life"* (G1p9), and almost half of participants reported to be identified with the characters *"It looks like I was seeing us a few years ago"* (B1s6). Consistent with literature the video aims to promote a narrative to describe the challenges and needs faced by parents in the process of educating a child with CP (Hoffman, Monge, Chou, & Valente, 2007; Janz et al., 1996; Korhonen et al., 2008).

In our findings were identified 13 parenting challenges and three tips of associated needs. The diagnosis moment was described with feelings such as anger or guilty, which is coincident with previous studies (Fernández-Alcántara et al., 2015; Whittingham, Boyd, Sanders, & Colditz, 2013).

Moreover, in addition to the difficulty to accept the diagnosis reported by Dieleman et al. (2019) we identified the amount of time needed to cope with this process, and how distinct this process could be from parent to parent. As referred in the literature, parents of children with CP have to perform a set of parenting tasks distinct from those performed by the parents of children with typical development (Whittingham et al., 2011). These tasks include, for example, continuous care, frequent medical appointments and sessions of rehabilitation therapies which require a diligent family management (e.g., decide which parent can manage their work time to be available to take care of the child). This time and task management are likely to affect the family pace and relationships (Nurullah, 2013).

Parents referenced the comparison behavior regarding the following aspects: comparisons made by themselves with typically developing children, but also with non-typically developing children and parents of both. The former is consistent with Nurullah (2013) findings in a sample of parents of children with developmental disabilities.

Besides this, some parents reported negative feelings regarding the comparisons made by others. Congruently, parents mentioned suffering from stigma and stressed the need to protect their children from stigma situations. Parental mental health was another subtheme identified in the participants talk. Our findings are consistent with previous studies indicating that parents of children with CP show high levels of stress and low mental health quality (e.g., Rentinck, Ketelaar, Jongmans, & Gorter, 2006).

Despite the negative consequences derived from the parental challenges associated to the process of taking care a child with a developmental disability, there were positives aspects referred by parents. For example, due to children high dependency level and lack of competencies, parents tend to develop a deep relationship with children and all the achievements are celebrated as big conquers.

Regarding three need themes, congruently with previous studies (e.g., Palisano et al., 2010), the needs for information were the most referenced by these parents. Participants reported the need for information about a multiplicity of topics related with parenting a child with CP (e.g., diagnose, prognostics, therapies) in a life-long horizon. The second needs theme more reported was the need for support, specifically during the days at neonatology and during the process of diagnosis acceptation. Parents reported that conversations with other parents in the same situation tend to help them in the established of a life plan that includes a child with CP, for example. Finally, regarding the needs for parental well-being parents stressed the exhaustion associated to taking care of a child with a disability and reported the need of have time to themselves.

CP is a condition with a life-long impact, therefore children will need health care in a life-long term. As long as the parents are the principal caregivers, this pattern of needs tend to maintain. Throughout the parents' life, the needs for information and support may decrease, due to the increased experiential knowledge about the disability, however the needs for parental well-being tend to increase, because the caregiving support has a reported impact in the mental and physical health of caregivers, mainly if they are immediate family (Brehaut et al., 2004; Davis et al., 2010)

Despite of the corpus of research on challenges and associated needs faced by parents of children with CP (e.g., Buran et al., 2009; Dieleman et al., 2019; Palisano et al., 2010), to the best of our knowledge, this study was the first with the purpose of mapping the context and timing in which challenges and needs occur in the parenting of children with CP . Therefore, this study findings are expected to help to further understand the factors characterizing the parenting challenges and needs Faced by this population.

Learning the specific moments [period(s) of the children's development] and contexts [Bronfenbrenner system] in which challenges and needs co-occur, may contribute to design tailored and accurate parenting interventions and establish good practices protocols (e.g., multidisciplinary teams available to support parents during the stay in the neonatology section at the hospital). As suggested by Rosenbaum (2003), intervention with children with CP need to consider and involve the whole family/caregivers and attend to their needs, values and competences, due to their potential role in promoting autonomy. In sum, findings of this study are expected to contribute to build a set of good

practices to be used in advocacy campaigns with the purpose of instigating policies and actions with positive impact in the experience of being a parent of children with CP.

Limitations and future studies

Despite our promising results, some limitations must be noted when interpreting the findings of this study. It is important stress the small size of the sample, the data collection in a limited geographic area and the inclusion of only one family member as respondent. Besides this, almost all the participants (81.8%) were woman. However, this fact should not have a significant impact on the results, because, the mother usually the primary caregiver of children with disabilities (e.g., Ones, Yilmaz, Cetinkaya & Caglar, 2005). Moreover, all participants attend to CP rehabilitation centers, where a family-centered approach is followed. It would be important to interview parents whose children are not in CP rehabilitation centers to compare the findings. Finally, for this study, only a single method of data collection was used. To have a broader picture of this phenomenoum, future research should consider using other ways to access the construct.

Previous literature suggested that the number and types of needs expressed by a family are different according to the level of mobility of the child and with the number of siblings (Palisano et al., 2010). Future research might include a bigger sample making it possible due to different groups, according to the GMFCS level and the number of siblings, allowing to make comparisons about the different groups and drawing conclusions.

References

Aisen, M. L., Kerkovich, D., Mast, J., Mulroy, S., Wren, T. A., Kay, R. M., & Rethlefsen, S. A. (2011). Cerebral palsy: Clinical care and neurological rehabilitation. *The Lancet Neurology, 10*(9), 844-852. doi:10.1016/s1474-4422(11)70176-4

Algood, C. L., Harris, C., & Hong, J. S. (2013). Parenting success and challenges for families of children with disabilities: An ecological systems analysis. *Journal of Human Behavior in the Social Environment, 23*(2), 126-136. doi:10.1080/10911359.2012.747408

Australian Cerebral Palsy Register Group. (2013). *Australian cerebral palsy register, report 2013*. Retrieved September 2, 2019 from https://www.cerebralpalsy.org.au/wp-content/uploads/2013/04/ACPRReport_Web_2013.pdf?_ga=2.254809867.2098862862.1571136902-1602113203.1570481994

Bax, M., Goldstein, M., Rosenbaum, P., Leviton, A., Paneth, N., Dan, B., ... Damiano, D. (2005). Proposed definition and classification of cerebral palsy, April 2005. *Developmental Medicine & Child Neurology, 47*(8), 571-576. doi:10.1017/s001216220500112x

Bazeley, P. & Jackson, K. (2013). *Qualitative data analysis with NVivo* (2nd edition). London, United Kingdom: Sage Publications.

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

Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., ... Rosenbaum, P. (2004). The Health of Primary Caregivers of Children with Cerebral Palsy: How Does It Compare With That of Other Canadian Caregivers?. *Pediatrics, 114*(2), 182–191. doi:10.1542/peds.114.2.e182

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*(7), 513-531. doi:10.1037/0003-066x.32.7.513

Buran, C. F., Sawin, K., Grayson, P., & Criss, S. (2009). Family needs assessment in cerebral palsy clinic. *Journal for Specialists in Pediatric Nursing, 14*(2), 86-93. doi:10.1111/j.1744-6155.2008.00176.x

Carr, L. J. (2005). Commentary on definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology, 47*(8), 508-510. doi:10.1111/j.1469-8749.2005.tb01183.x

Cheshire, A., Barlow, J. H., & Powell, L. A. (2010). The psychosocial well-being of parents of children with cerebral palsy: A comparison study. *Disability and Rehabilitation, 32*(20), 1673-1677. doi:10.3109/09638281003649920

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health and Development, 36*(1), 63–73. doi:10.1111/j.1365-2214.2009.00989.x

Deci, E. L., & Ryan, R. M. (2000). The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry*, *11*(4), 228-268. doi:10.1207/s15327965pli1104_01

Dieleman, L. M., Van Vlaenderen, R., Prinzie, P., & De Pauw, S. S. W. (2019). Parents' need-related experiences when raising an adolescent with cerebral palsy. *Advances in Neurodevelopmental Disorders, 3*(2), 204-219. doi:10.1007/s41252-019-00111-3

Diu, N. L., & Lockhart, K. (2015, June 19). *Father's Day* [Video file]. Retrieved from https://s.telegraph.co.uk/graphics/projects/fathers-days/index.html

Dockett, S., & B. Perry. (2007). *Transitions to school: Perceptions, expectations and experience*. Sydney, NSW, Australia: UNSW Press book.

Eurostat. (2017). European Statistical Office Website. Retrieved from https://ec.europa.eu/eurostat/statistics-explained/index.php/Fertility_statistics

Fernández-Alcántara, M., García-Caro, M. P., Laynez-Rubio, C., Pérez-Marfil, M. N., Martí-García, C., Benítez-Feliponi, Á., ... Cruz-Quintana, F. (2015). Feelings of loss in parents of children with infantile cerebral palsy. *Disability and Health Journal, 8*(1), 93-101. doi:10.1016/j.dhjo.2014.06.003

Gorter, J. W., Rosenbaum, P. L., Hanna, S. E., Palisano, R. J., Bartlett, D. J., Russell, D. J., ... Wood, E. (2004). Limb distribution, motor impairment, and functional classification of cerebral palsy. *Developmental Medicine & Child Neurology, 46*(7), 461-467. doi:10.1017/s0012162204000763

Graham, H. K., Rosenbaum, P., Paneth, N., Dan, B., Lin, J. P., Damiano, D. L., ... Lieber, R. L. (2016). Cerebral palsy. *Nature Reviews Disease Primers, 2*(15082), 1-24. doi:10.1038/nrdp.2015.82

Groeneveld, M. G., Vermeer, H. J., Linting, M., Noppe, G., van Rossum, E. F. C., & van IJzendoorn, M. H. (2013). Children's hair cortisol as a biomarker of stress at school entry. *Stress: The International Journal on the Biology of Stress*, *16*(6), 711-715. doi:10.3109/10253890.2013.817553

Hepworth, D., Rooney, R., Rooney, G., & Strom-Gottfried, G. (2013). *Direct social work practice: Theories and skills* (9th edition). Belmont, CA, US: Brooks/Cole Cengage Learning.

Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess, S. A., & Ladany, N. (2005). Consensual qualitative research: An update. *Journal of Counseling Psychology, 52*(2), 196-205. doi:10.1037/0022-0167.52.2.196

Hoffman, B. R., Monge, P. R., Chou, C.-P., & Valente, T. W. (2007). Perceived peer influence and peer selection on adolescent smoking. Addictive Behaviors, 32(8), 1546-1554. doi:10.1016/j.addbeh.2006.11.016

Janz, N. K., Zimmerman, M. A., Wren, P. A., Israel, B. A., Freudenberg, N., & Carter, R. J. (1996). Evaluation of 37 AIDS prevention projects: Successful approaches and barriers to program effectiveness. *Health Education Quarterly, 23*(1), 80-97. doi:10.1177/109019819602300106

Johnson, A. (2002). Prevalence and characteristics of children with cerebral palsy in Europe. *Developmental Medicine & Child Neurology, 44*(9), 633-643. doi:10.1017/s0012162201002675

Korhonen, T., Huizink, A., Dick, D., Pulkkinen, L., Rose, R., & Kaprio, J. (2008). Role of individual, peer and family factors in the use of cannabis and other illicit drugs: A longitudinal analysis among Finnish adolescents twins. *Drug and Alcohol Dependence*, *97*(1-2), 33-43 doi:10.1016/j.drugalcdep.2008.03.015

Krigger, K. W. (2006). Cerebral palsy: An overview. *American Family Physician, 73*(1), 91-100.

Kurt, E. E. (2016). Definition, epidemiology, and etiological factors of cerebral palsy. In K. M. Gunel (Ed.), *Cerebral Palsy: Current Steps* (pp. 3-20). London, United Kingdom: IntechOpen Limited. doi:10.5772/64768

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

Larkey, L. K., & Hecht, M. (2010). A Model of effects of narrative as culture-centric health promotion. *Journal of Health Communication, 15*(2), 114-135. doi:10.1080/10810730903528017

Madill, A. (2012). Interviewing and interview techniques. In H. Cooper (Ed.), *American Psychological Association handbook of research methods in psychology*. Washington, DC, US: American Psychological Association.

Magnusson, D., & Allen, V. L. (1983). *Human development: An interactional perspective*. New York, NY, US: Academic Press.

Mendenhall, A. N., & Mount, K. (2011). Parents of children with mental illness: Exploring the caregiver experience and caregiver-focused interventions. *Families in Society: The Journal of Contemporary Social Services, 92*(2), 183-190. doi:10.1606/1044-3894.4097

Niesel, R. & Griebel, W. (2007). Enhancing the competence of transitions systems through coconstruction. In A. W. Dunlop & H. Fabian (Eds.), *Informing Transitions in the Early Years: Research, Policy and Practice*, (pp. 21-32). London, United Kingdom: McGraw-Hill Education.

Novak, I., Mcintyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., ... Goldsmith, S. (2013). A systematic review of interventions for children with cerebral palsy: State of the evidence. *Developmental Medicine & Child Neurology, 55*(10), 885-910. doi:10.1111/dmcn.12246

Nurullah, A. S. (2013). "It's really a roller coaster": Experience of parenting children with developmental disabilities. *Marriage & Family Review*, *49*(5), 412-445, doi:10.1080/01494929.2013.768320

Ones, K., Yilmaz, E., Cetinkaya, B., & Caglar, N. (2005). Assessment of the Quality of Life of Mothers of Children with Cerebral Palsy (Primary Caregivers). *Neurorehabilitation and Neural Repair, 19*(3), 232-237. doi:10.1177/1545968305278857

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997) Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology, 39*(4), 214-223. doi:10.1111/dmcn.1997.39.issue-4

Palisano, R. J., Almarsi, N., Chiarello, L. A., Orlin, M. N., Bagley, A., & Maggs, J. (2010). Family needs of parents of children and youth with cerebral palsy. *Child: Care, Health and Development, 36*(1), 85-92. doi:10.1111/j.1365-2214.2009.01030.x

Raina, P., O'Donnell, M. Rosenbaum, P., Brehaut, J., Walter, S. D., Russel, D. ... Wood, E. (2005) The health and well-being of caregivers of children with cerebral palsy. *Pediatrics, 115*(6), 626-636. doi:10.1542/peds.2004-1689

Rentinck, I. C. M., Ketelaar, M., Jongmans, M. J., & Gorter, J. W. (2007). Parents of children with cerebral palsy: A review of factors related to the process of adaptation. Child: Care, Health and Development, 33(2), 161-169. doi:10.1111/j.1365-2214.2006.00643.x

Rimm-Kaufman, S. E., & Pianta, R. C. (2000). An ecological perspective on the transition to kindergarten. *Journal of Applied Developmental Psychology, 21*(5), 491-511. doi:10.1016/s0193-3973(00)00051-4

Rosenbaum, P. (2003). Cerebral palsy: What parents and doctors want to know. British Medical Journal, 326 (7396), 970-974. doi:10.1136/bmj.326.7396.970

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., ... Jacobsson, B. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine & Child Neurology Supplement, 49*(6), 8-14. doi:10.1111/j.1469-8749.2007.tb12610.x

Russ, S. J., Herbert, J., Cooper, P., Gunnar, M. R., Goodyer, I., Croudace, T., & Murray, L. (2012). Cortisol levels in response to starting school in children at increased risk for social phobia. *Psychoneuroendocrinology, 37*(4), 462-474. doi:10.1016/j.psyneuen.2011.07.014

Singhal, A., & Rogers, E. M. (2002). A theoretical agenda for entertainment education. *Communication Theory, 12*(2), 117-135. doi:10.1111/j.1468-2885.2002.tb00262.x

Slater, M. D., Rouner, D., & Long, M. (2006). Television dramas and support for controversial public policies: Effects and mechanisms. *Journal of Communication, 56*(2), 235-252. doi:10.1111/j.1460-2466.2006.00017.x

Surveillance of Cerebral Palsy in Europe. (2002). Prevalence and characteristics of children with cerebral palsy in Europe. *Developmental Medicine & Child Neurology, 44*(9), 633-640. doi:10.1017/s0012162201002675

Trabacca, A., Vespino, T., Di Liddo, A., & Russo, L. (2016). Multidisciplinary rehabilitation for patients with cerebral palsy: Improving long-term care. *Journal of Multidisciplinary Healthcare, 9,* 455-462. doi:10.2147/jmdh.s88782

Whittingham, K., Wee, D., & Boyd, R. (2011). Systematic review of the efficacy of parenting interventions for children with cerebral palsy. *Child: Care, Health and Development, 37*(4), 475-483. doi:10.1111/j.1365-2214.2011.01212.x

Whittingham, K., Boyd, R. N., Sanders, M. R., & Colditz, P. (2013). Parenting and prematurity: Understanding parent experience and preferences for support. *Journal of Child and Family Studies, 23*(6), 1050-1061. doi:10.1007/s10826-013-9762-x