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ORIGINAL PAPER

Parents' Need-Related Experiences When Raising an Adolescent with Cerebral Palsy

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Abstract

Objectives Raising a child with cerebral palsy (CP) has been shown to strongly affect parents' well-being and is often described as challenging or complex. Although quantitative studies have shown that these parents are at risk for increased levels of stress, a more comprehensive and in-depth insight into their experiences is needed in order to better understand these parents and to effectively support them. By relying on a self-determination theory perspective, this qualitative study puts the basic psychological needs for autonomy, relatedness, and competence forward as a structuring framework to explore both possibilities for need-satisfying experiences as well as risks for need-frustrating experiences when raising an adolescent with CP.

Methods Nine parents of adolescents with CP, aged 10 to 18 years, participated in an in-depth interview concerning their need-related experiences in raising their son or daughter with CP. The data were analyzed with deductive thematic analysis.

Results Parents' experiences were classified into five themes and nine subthemes. Next to the need-related themes, the themes "accepting the diagnosis" and "uncertainty about the future" were also identified as essential to capture parents' experiences.

Conclusions Although raising an adolescent with CP entails threats for parents' need for autonomy, relatedness, and competence, it can also offer opportunities to feel closely connected with others and to feel effective when achieving unexpected goals. In order to fully capture parents' experiences, we also need to take into account their acceptance of the diagnosis and their worries about the future.

Keywords Cerebral palsy · Parenting · Need-related experiences · Self-determination theory · Qualitative research

Cerebral palsy (CP) is a chronic neuro-developmental disorder, due to a non-progressive brain lesion, causing motor disability (Odding et al. 2006). Children with CP experience dysfunctions in their muscle tone, movement, or posture which cause activity limitations. Due to differences in the size, type, and location of the brain lesion, there is a lot of variety in the severity and type of dysfunctions that children experience (Rosenbaum et al. 2007). In addition, these children often experience comorbid physical, cognitive, and social-emotional impairments, such as epilepsy, intellectual disability, and peer problems (Rosenbaum et al. 2007). As a consequence, parents are faced with insecurity about the child's development, they have to consult medical experts on a regular basis, organize specific healthcare, and make practical adaptations to their daily life. Parents might also need to adapt their expectations with regard to their parent-role, learn specialized caregiving behaviors, and re-organize their family life (Pousada et al. 2013).

These adaptations and efforts can seriously affect parents' physical and mental health or well-being. Research has convincingly shown that parents of children and adolescents with CP—as a group and compared to parents of typically developing children—are at risk for decreased levels of well-being and increased psychosocial

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difficulties, such as stress, depressive feelings, and anxiety (Brehaut et al. 2004; Guyard et al. 2017; Parkes et al. 2011; Pousada et al. 2013). Yet, not all parents of children with CP experience mental health problems or high levels of stress (Pousada et al. 2013). This variation in the well- or ill-being of parents of children with CP has been linked with child (e.g., the presence of comorbid problems) and parent characteristics (e.g., parents' self-efficacy) and contextual factors (e.g., social support) (Guyard et al. 2017; Majnemer et al. 2012; Manuel et al. 2003; Pousada et al. 2013; Raina et al. 2005).

Although these findings, which are mostly based on quantitative studies, indicate that raising a child with CP is challenging, they do not provide an in-depth insight into these parents' experiences. That is, it is not clear why exactly parents experience higher levels of stress or psychosocial difficulties. A more comprehensive and in-depth understanding allows to identify the most important targets for parent support and to develop more tailored interventions or support for families.

A theory that might advance this comprehensive and in-depth understanding is the Self-Determination Theory (SDT) (Deci and Ryan 2000). SDT is an organismic meta-theory on human development and socialization (Ryan and Deci 2017). A central tenet in SDT is that every individual has an innate tendency towards psychological growth and development, thereby increasingly evolving towards an integrated identity (i.e., the process of internalization). This process of growth and development depends largely on the extent to which a social environment supports or thwarts the three basic psychological needs of that individual. The three innate needs are specified in SDT as "innate psychological nutriments that are essential for ongoing psychological growth, integrity, and well-being" (Deci and Ryan 2000, p. 229) and concern the need for autonomy (i.e., the need to experience self-direction and psychological freedom), relatedness (i.e., the need to feel connected with others), and competence (i.e., the need to feel effective in accomplishing goals) (Deci and Ryan 2000). When these needs are satisfied, people experience a sense of authenticity, reciprocal care, and personal effectiveness. The frustration of these needs, however, results in feelings of pressure or obligation, social alienation or loneliness, and personal failure. Extensive research has shown that need satisfaction is essential for well-being, happiness, and optimal self-development, whereas need frustration makes people vulnerable for ill-being, passivity, and psychopathology (Deci and Ryan 2000).

Although research did not directly examine the basic psychological needs of parents of children with CP, previous findings from qualitative and quantitative studies can be interpreted through the lens of SDT. That is, several findings concerning parents' experiences can be interpreted as challenges for need satisfaction or even risks for need thwarting. For instance, many parents of children and adolescents with CP need to give up or change their professional career, which could be interpreted as a threat for their need for autonomy (Brehaut et al. 2004). Parents also experience a lot of restrictions to develop their own interests in their daily life due to the constant care they need to provide and the lack of people who can provide temporary care (Alaee et al. 2015). In addition, parents report limited time to spend as a couple and indicate that raising a child with CP places strains on their relationship, findings that could indicate threats for parents' need for relatedness (Alaee et al. 2015; Davis et al. 2009; Florian and Findler 2001). Parents of children and adolescents with CP have also reported to feel lonely and to lack social contacts because the intense healthcare and practical difficulties limit their possibilities to join activities with friends or families or because their life has changed so much that it becomes difficult to connect with friends (Alaee et al. 2015; Davis et al. 2009). Threats for parents' need for competence can be found in parents' reports of difficulties when providing specialized care and organizing medical care or when interpreting child behavior and responding in an adaptive way (Huang et al. 2010; Whittingham et al. 2011).

In addition, the SDT framework allows to identify and structure possibilities for need satisfaction. Although positive experiences have been addressed less in both quantitative and qualitative research among parents of children with CP, and children with developmental disabilities in general (Hastings and Taunt 2002), some findings do suggest opportunities for need-satisfying experiences. Parents reported, for instance, that having a son or daughter with CP resulted in a new social network, which can be interpreted as satisfaction of their need for relatedness (Davis et al. 2009). The finding that some families report strong family cohesion and close relationships also suggests possibilities for a parent's relatedness satisfaction (Björquist et al. 2015; Fiss et al. 2013). Parents' feelings of competence might also be satisfied when their child or adolescent reaches a goal or when they notice that the specialized healthcare they organize or the exercises that they do at home are paying off (Davis et al. 2009).

Although there are no studies examining the basic psychological needs among parents of children with CP, a recent study did apply the SDT framework to improve the understanding of parents' experiences in the context of raising a child or adolescent with autism spectrum disorder (Dieleman et al. 2018). In this qualitative study, parents' diverse experiences were captured in a comprehensive way by relating the majority of them to parents' need for autonomy, relatedness, and competence. The SDT framework did not only allow to identify challenges to parents' psychological needs (e.g., feelings that the care for their child takes over their lives indicate autonomy frustration) but made it also possible to identify opportunities for need satisfaction (e.g., experiences of a strengthened partner relation indicate relatedness satisfaction). So, these findings point towards the usefulness and meaningfulness of applying the SDT framework when examining parents' experiences in the context of raising a child with special needs.

In sum, several quantitative studies have reported that parents of children and adolescents with CP are vulnerable to experience decreased levels of well-being. Nevertheless, a comprehensive qualitative approach is needed to grasp more in-depth the specific challenges and to identify opportunities to support these parents and enhance their well-being. Therefore, this study aims to advance the understanding of parents' experiences while raising an adolescent with CP by conducting in-depth interviews. In order to capture the complexity and to structure parents' experiences, the three basic psychological needs, as identified by the SDT, were used as a structuring framework. More specifically, we examine whether parents' experiences can be related to frustration or satisfaction of their need for autonomy, relatedness, and competence.

Method

Participants

A total of 12 parents (6 mothers and 3 parent couples) of adolescents with CP (4 girls, 5 boys) participated in this study. The adolescents were aged between 10 and 18 years ($M =$ 13.89). All adolescents were diagnosed with spastic CP and were living at home. One adolescent (case 3) spent one night per week in school. All parents reported comorbid diagnoses (such as epilepsy or autism spectrum disorder). More demographic information is presented in Table 1.

Procedure

This qualitative study is part of a large, on-going, longitudinal study on parents of children with CP. Parents were first recruited in 2015 through seven Belgian service centers for children with physical disabilities. Initially, 135 parents were recruited to participate in this broad quantitative study. During the follow-up study, 1 year later, parents were asked if they would like to be contacted to participate in an interview about their experiences as a parent. In total, 78 parents indicated that they would like to be contacted for this interview.

In order to participate in the interview, families had to meet two inclusion criteria: the child (1) had received a diagnosis of CP, (2) was aged between ten and eighteen years, and (3) his/her principal residency was at home with the parent(s). Parents could choose to participate alone or as a couple. In total, 18 parents who met these criteria were randomly selected and contacted to participate in the interview. The final data sample consisted of ten interviews conducted with seven mothers and three couples. One interview was strongly affected by the mothers' psychiatric problems and because we did not receive answers to the questions, this interview was not included in further analysis. The final sample, thus, comprised 9 interviews with six mothers and three couples.

Parents received information about the study prior to the interview and informed consent was obtained from all participants. The study received ethical approval from the organizing university's Institutional Review Board.

Measures

Prior to the interview, parents were asked to provide demographical information about their family (e.g., educational level parent). In addition, the child's gross motor function was assessed with the Gross Motor Function Classification System Family Report (GMFCS-FR; Palisano et al. 2008). The GMFCS is a classification system that determines the severity of CP on the basis of the child's functional abilities and needs of assistive technology for mobility. The GMFCS identifies five levels with children classified in level I being able to walk without restrictions but having limitations in more advanced motor skills and children classified in level V having very limited motor abilities. The family report of the GMFCS has been shown to be a reliable method for measuring gross motor function (Morris et al. 2004). Most adolescents had relatively good functional motor abilities (as indicated by level 1 and 2 on the GMFCS), but one adolescent (case 3) was not able to sit independently and to control his own head or body posture (i.e., level V on the GMFCS) (see Table 1).

Next, parents participated in a semi-structured interview focusing on their need-related experiences related to raising a child with CP. All interviews were conducted by the second author of this manuscript. At the beginning of the interview, the three psychological needs were briefly introduced to parents. This was done by mentioning that there are three themes, among other experiences, that might be interesting to discuss: parents' relationships with others (i.e., relatedness), feelings of freedom to do things they want (i.e., autonomy), and their feelings of efficacy (i.e., competence). Parents were incited to talk freely about their personal experiences. Throughout the interview, parents were asked how raising a child with CP affected their need for relatedness (e.g., *How does raising a child with CP influence your social life?*), autonomy (e.g., *How does raising a child with CP influence your freedom to make your own choices?*), and competence (e.g., *Do you feel* *capable to deal with the challenges that raising a child with CP brings about?*). In order to fully capture parents' experiences, questions were asked in a neutral way (e.g., *How do you experience that?*) or the interviewer referred to both negative and positive experiences (e.g., *How does it affect your relationship, in a negative or/and a positive way?*). In addition to these three main themes, parents could introduce other topics that they deemed important for their experience. In order to incite parents to introduce topics that were unrelated to the three main themes, the interviewer clearly mentioned that the three main themes were only potential interesting themes and that parents could talk about any experience that they wanted. Therefore, the interview schedule was handled flexibly, and individual topics were followed by probes.

Data Analysis

The interviews were digitally recorded and lasted between 31 and 87 minutes. The verbatim transcripts were analyzed in accordance with the principles of thematic analysis (Braun and Clarke 2006) using the software program NVivo (QSR International 2018). Because the three psychological needs described by SDT were used as a framework to structure parents' experiences, the data analysis relied on deductive thematic analysis (Braun and Clarke 2006). Nevertheless, because the interview schedule was handled flexibly, it was also possible to explore additional themes that are essential to fully capture parents' experiences. The data analysis consisted of recurrent phases of reading through the interviews, coding the data, and creating (sub)themes. The research team conducting the analysis included trained researchers with diverse personal and professional backgrounds (i.e., the team included researchers with a strong theoretical background in SDT and a researcher with only limited background in SDT).

First, the second author (who had a limited background in SDT) familiarized herself with the data by reading the interviews several times and noting comments about the meaningful and relevant information in the interview. Next, the first five interviews were coded openly, resulting in an extensive list of initial codes. These initial codes were organized into potential themes and subthemes by the first two authors (with the first author having a theoretical background in SDT). After this, the first two authors evaluated whether the codes within a (sub)theme formed a coherent pattern and whether they accurately represented parents' experiences. Less relevant (sub)themes were removed and a final list of (sub)themes was formulated. Finally, each theme was defined and representative quotes were selected. This process of data analysis, in which two researchers discussed and reflected upon the codes until consensus was reached, reduced personal biases in the analysis.

In order to ensure credibility, each participant was presented with the transcribed interview and was given the chance to

Table 1 Demographic characteristics of participants

Parent information and family structure					Child information			
Participant (age)	Marital status	Education level[a]	Employment status	Number of children	Gender (age)	Educational level	Functional abilities (GMFCS)	Additional diagnoses[b]
1. Mother (49)	Single	Higher education	Part-time	2	Girl (13)	Special primary education	Level 2	Epilepsy, learning disorder, language disorder
2. Mother (43)	Married	Higher education	Part-time	2	Girl (13)	Special primary education	Level 2	Dyslexia
3. Mother (45)	Co-habiting with biological father of child	Higher education	Full-time	3	Boy (10)	Special primary education	Level 5	Epilepsy
4. Mother (48) and father (56)	Married	Both higher education	M: Part-time F: Full-time	2	Boy (14)	Special secondary education	Level 1	Problems with short-term memory
5. Mother (45)	Married	Higher education	Part-time	2	Girl (13)	Regular secondary education	Level 1	ASD
6. Mother (55) and father (42)	Married	Both secondary education	M: Part-time F: Full-time	1	Boy (15)	Special secondary education	Level 2	Diabetic type 1, dyscalculia, language disorder
7. Mother (41) and father (50)	Married	M: Higher education F: Secondary education	Both full-time	3	Boy (18)	Special secondary education	Level 1	ADHD, ASD, epilepsy
8. Mother (43)	Divorced	Higher education	Part-time	2	Boy (13)	Special secondary education	Level 2	Visual disorder
9. Mother (47)	Married	Secondary education	Housewife	3	Girl (16)	Regular secondary education	Level 2	Visual disorder, Sprengel syndrome

[a] Higher education = college or university

[b] ASD = Autism Spectrum Disorder

add information or to comment on the interview. In addition, we ensured credibility through data triangulation (i.e., using multiple researchers for data analyses). Personal biases in the data analysis were limited through the group process, in which the different researchers discussed and reflected together upon the list of (sub)themes.

Results

The analyses of parents' experiences identified five important themes. Table 2 presents the identified themes and subthemes and the frequency of each subtheme. The frequencies indicate that all subthemes were well represented within the interview data. Three themes could be structured within the framework of the psychological needs and were labeled as challenges for parents' need for (1) autonomy, (2) relatedness, and (3) competence. The fourth and fifth theme that were retained concerned (4) the process of accepting the diagnosis, and (5) the uncertainty about the future.

Challenges for Parents' Need for Autonomy

A first important theme within parents' experiences related to raising a child with CP refers to challenges for parents' need for autonomy. All participants reported diverse experiences in which their need for autonomy was frustrated. Parents felt that they needed to give up a lot, such as own interests and professional ambitions. These autonomy-frustrating experiences encompass an affective component of regret and sadness (e.g., feeling different from other families) and a more practical component (e.g., re-organizing family routines to adapt to the therapy schedule of the adolescent with CP). Parents indicated that the limitations to their autonomy have short-term and long-term consequences. A short-term consequence, for instance, is that parents feel exhausted and have limited opportunities to relax. A long-term consequence, for example, is the limitation of career opportunities. This theme comprises two specific challenges: (1) experiencing restrictions in daily life and (2) limitations in pursuing an own career.

Experiencing Restrictions in Life

The subtheme "experiencing restrictions in life" refers to the affective experience to be different from other families and more specifically the feeling to have less opportunities in life than other families, and the regret and sadness about these differences. Parents feel like they have to give up their autonomy because their adolescent needs a lot of support, because the management of the healthcare and the therapies are time-consuming, and because their son or daughter is not able to do certain activities (e.g., go for daytrip with the bike). Although parents indicate that their son or daughter benefits from these adaptations, they experience them at the same time as restrictive. Eight parents indicated that they did not have had time for themselves since their child with CP was born. An important factor that contributes to this feeling of restriction is that parents take full responsibility for the care at home and are not likely to allow someone else to take care of their son or daughter. Parents perceive themselves as the only ones who can

Table 2 Frequency of themes and subthemes

Themes	Subthemes	Frequency of interviews[a]	Total frequency[b]
Challenges for parent's need for autonomy			
	Experiencing restrictions in life	9	57
	Limitations in the pursuit of a professional career	6	8
Challenges for parent's need for relatedness			
	An intense relationship between parent and child	4	8
	Challenges for relatedness with siblings	5	6
	Challenges for relatedness with partner	7	39
	Challenges for relatedness with the broader network	9	38
	Challenges for relatedness with healthcare providers	6	26
Challenges for parent's need for competence			
	Achieving the unexpected	4	9
	Feeling exhausted	7	18
	Feeling powerless	4	6
Accepting the diagnosis		7	15
The uncertainty about the future		6	9

[a] Number of interviews in which the (sub)theme was identified

[b] Total number of references to the subtheme across all interviews

provide the best care, or they feel like other people (e.g., family, friends, external babysit) are not willing or are too scared to take care of a child with a disability.

> “We love our son with all our hearts, but sometimes we say ‘if only things were different’. A child of ten, twelve years old already starts to do things alone. You can do more things together, you have more free time. We don’t have that.” (Mother 3)

> “In fact, I don’t do anything for myself anymore. I think that if you have a ‘normal’ family with two children, you do have time to practice a sport, for example. But the extra care – that I enjoy giving her - makes that I do not find the time for that.” (Mother 2)

Limitations in the Pursuit of a Professional Career

Another important element within the challenge for parents’ need for autonomy concerns the fact that at least one of the parents has less chances to pursue a professional career. Often, one of the parents decides to work less, to work closer to home, or to give up professional ambitions. In six participating families, the mother decided to alter her professional aspirations. Half of these mothers experienced this as extremely regrettable, whereas the other mothers did not mind it strongly. One mother (mother 3), on the other hand, decided to continue to work full-time because her job gave her a lot of satisfaction and the financial advantage allowed the family to adapt their house and their holidays to the needs of their son with CP.

> “In the beginning, when she went to the nursery, I worked full-time. But then I had to start working part-time because it didn’t work anymore. T. had to sleep in the afternoon and that was impossible at school. And she had to go to therapy, to physiotherapy. So I had no other option than to work part-time.” (Mother 1)

> “I have thought about working part-time or stopping completely. But I would not be able to miss it. That is a personal decision.” (Mother 3)

Challenges for Parents’ Need for Relatedness

A second important theme within parents’ experiences concerned the challenges for their need for relatedness. Raising a child with CP brings about additional challenges that can put pressure upon one’s relationships both within the family and within the broader social network. On the other hand, parents also mentioned some opportunities for need satisfaction. This theme consists of five subthemes: (1) an intense and close relationship between parent and child, (2) challenges for relatedness with siblings, (3) challenges for relatedness with partner, (4) challenges for relatedness with the broader social network, and (5) challenges for relatedness with healthcare providers.

An Intense Relationship Between Parent and Child

Parents experience the relationship with their adolescent with CP on the one hand as more special and precious than with their other children, but at the same time describe it as more strenuous and exhausting. Parents attribute the latter experience to the intense physical and emotional support that their son/daughter needs. Parents feel that their child strongly relies on them and that they are indispensable for their child. The parents stressed that they enjoy giving this extra support but that it is also very tiring and exhausting for them.

> “Let us say that I am partially her shadow. So, in a way we stick to each other.” (Mother 1)

> “Everybody loves his/her child but this relationship is a lot more special. Yes, it really is very special. Very precious. Also more burdensome. But as mother you do everything for your child.” (Mother 3)

Challenges for Relatedness with Siblings

Due to the intense support that adolescents with CP need, parents feel like their relationship with their other children is put under pressure. Parents feel like they (too) often ask siblings to take into account and to adjust themselves to the disability of their brother or sister. Parents often have to refuse their other children to do activities because they are not accessible for the child with CP or because the child with CP is not able to keep up with the activity. In order to allow the siblings to do these activities anyway, families split themselves up and do activities separately. For example, the mother does an activity with the child(ren) without CP, while the father and the child with CP do an activity adapted to the possibilities of the child. This solution, however, gives parents the feeling to be less connected as a family. Other families organize special moments or activities with the sibling because they find it important that the sibling also receives personal attention.

> “Always split up. Yes, nine out of ten times, we are split up. So our whole family is always split up and X (brother of the child with CP) has been restricted because of that. Since he was a toddler.” (Mother 2)

> “Y (brother of the child with CP) can sometimes say - while laughing- that everything evolves around A (child

> with CP). And yes, you do take into account the one child more than the other.” (Mother 8)

Challenges for Relatedness with Partner

Parents indicated that raising a child with CP impacted the relationship with their partner, both in a positive and a negative way. In five interviews, parents indicated that their relationship with their partner became more intense due to the disability of their son/daughter. Thanks to the challenges that they face together, parents grow closer together and find ways to support each other. When one partner is feeling exhausted, worried, or scared, the other partner increases his/her support and helps the exhausted partner to persevere and to stay positive and hopeful. The practical difficulties that come with CP also force parents to collaborate more in order to organize their family life. When parents are able to work as a team and succeed in this organization, they experience a feeling of pride and accomplishment. On the other hand, parents also reported negative effects on the relationship with their partner. Parents especially experienced the fact that they often have to split up the family while doing activities as negative. Parents also feel that they have little time to do things as a couple and that their relationship is dominated by care tasks.

> “We were lucky: when the one person felt down, the other was not. And we always have cheered each other up the first two years, constantly.” (Mother 4)

> “For us, it was positive. We have always supported each other a lot.” (Father 6)

> “You always have to split up, so you always do everything separate. Yes, I think that drove us apart. And by the time you realize it, it’s too late.” (Mother 8)

Challenges for Relatedness with the Broader Network

Raising a child with CP also affects parents’ relationships with their broader network, including friends and family. Parents shared both positive and negative experiences related to this subtheme. Six participants indicated that their family, and mostly their parents, represent an important source of support. Three participants stated that the presence of CP in their family had no negative impact whatsoever on their social relationships. Friendships that lasted, despite the difficult situation and parent’s lack of time, actually become extra meaningful and valuable. Parents highly appreciate acts of support from their friends and family. Parents mentioned, for example, feeling supported when their family visited their child when he/she is hospitalized. Some parents also mentioned that they developed new friendships with other parents of children with disabilities because these parents understand them better and can support them better.

Next to these positive experiences, parents also reported multiple experiences of loss. Four participants felt like they had lost a lot of friends due to a lack of time to be with friends, practical issues making it difficult to join activities with other families (e.g., activities that have a mismatch with the motor capacities of their adolescent), and a lack of energy (i.e., parents feel too tired for social activities). Participants also indicated that, at times, they do not feel understood by their friends and family because they are not able to evaluate the impact of the disability correctly. This lack of understanding can be manifested in negative comments about or in the minimization of the disability, which gives parents the feeling to be all alone. Some families also experience social exclusion in the form of pitying looks, whisperings, laughter, being stared at, and exclusion of their adolescent during certain activities.

> “We lost a lot of friends. It takes a while, it does not happen from one day to the other. But eventually, by having a child with CP, you experience limitations. You can’t go everywhere. You can’t be on time. And sometimes you can’t join. And in the end, you do lose some friends. But, on the other hand, there are also people with whom you build a closer relationship. People who understand you very well and even help you. And now that he (i.e., child with CP) is becoming older, he has a lot of friends with CP and we are also close friends of their parents. We do a lot of things together. So actually, those are new friendships that developed with parents of similar children. And that – not that I don’t like my other friends - has become something very valuable.” (Mother 3)

> “We have noticed a lot of denial in people. We saw the severity of the situation and we knew it was very serious. And in the beginning my mother mostly minimized it. And that was hard for me. She was like “everything will be fine”. And I did not want to hear that.” (Mother 9)

Challenges for Relatedness with Healthcare Providers

Families of children with CP have frequent, intense, and long-lasting contacts with healthcare providers. The healthcare providers mentioned by the participants include teachers and the management of schools, physiotherapists, occupational therapists, counselors who offer at-home-support, and doctors and nurses of hospitals. Parents mentioned diverse positive experiences with these healthcare providers. Parents mostly valued healthcare providers who are genuinely interested in the well-being of their family and child. Parents experience healthcare providers as supportive when they notice and value the strengths of their son/daughter (instead of focusing only on the deficits and impairments). Parents also feel more connected with the healthcare providers when they help to look for solutions if the child is not (yet) able to do something. By doing this, healthcare providers help parents to see possibilities and motivate them to continue offering the intense health care that their son/daughter needs.

The relatedness with healthcare providers is undermined, however, when parents feel that healthcare providers underestimate their child's abilities, do not support their child to improve, and only focus on problems or impairments. A lack of or a negative style of communication also harms the relationship with healthcare providers.

> "We could not stand that, every time we went to his school they said: 'he cannot do this, he cannot do that, …' ". (Mother 6)

Challenges for Parents' Need for Competence

A third important theme within parents' experiences was framed as challenges for their need for competence. This theme consists of three subthemes: (1) achieving the unexpected, (2) feeling exhausted, and (3) feeling powerless. Achieving the unexpected refers to parents' feelings of accomplishment, efficacy, and pride when their adolescent has reached more goals or acquired more skills than they or the healthcare providers had expected. Feeling exhausted concerns the finding that parents are sometimes faced with situations of which they know how to handle them, but they cannot because they lack the energy. In these moments, parents' capacities are insufficient to deal with the "workload" of caring for an adolescent with CP. Feeling powerless encompasses situations in which parents do not know what do to or feel like there is nothing they can do to change the situation.

Achieving the Unexpected

The majority of the parents indicated that they initially had received a negative or uncertain prognosis about their child's developmental possibilities. However, some parents noticed that the efforts of them and their child (e.g., following intensive therapy, using certain devices such as night orthoses, doing extra physical therapy) resulted in unexpected achievements, such as being able to ride a bike. To beat the odds and to reach these goals or acquire these skills, both parents and their child really have to persevere and keep going when things are difficult. So, reaching these unexpected achievements really gave parents a feeling of accomplishment, efficacy, and pride. These feelings of competence, in turn, strengthen parents' belief in themselves and in their son/daughter, fostering their drive to further strive for improvement.

> "As long as I could support her in the right direction, I felt good." (Mother 1)

> "It makes it up for me to see them (i.e., her children with a disability), now that they are older, and I think "wow". Maybe I didn't fail (as a mother), after all." (Mother 9)

Feeling Exhausted

All parents refer to the impact of the enduring health care and support their son/daughter with CP needs, including both practical and emotional aspects. For instance, parents need to offer practical support during daily activities such as eating or getting dressed because the physical disability impairs the adolescent to do this independently. Some health care tasks strongly impact on parents' own physical health. For instance, due to motor difficulties, some parents also need to carry or lift their son/daughter. Parents also need to offer a lot of emotional support in order to motivate their son/daughter to follow specialized therapy (e.g., physiotherapy), do specific exercises on a daily basis, and use devices such as splints. Sometimes adolescents refuse to do these activities because they can be painful or boring or because they do not seem to improve their functioning. Motivating the adolescent to keep doing these difficult and sometimes painful activities can, thus, be difficult for parents. The intense level of the required practical, physical, and emotional support can cause feelings of exhaustion in parents. In these moments, parents still know how to offer practical support or still know that they should motivate their child but they merely lack the energy to do so.

> "I have had a burn-out. And I attribute this to the fact that I completely forgot myself for many years." (Mother 2)

> "It was hard because L. could not move himself. The only thing he could do was lift his bottom and bounce his head. So, every time his arm was not in the right position, he started to cry and my wife had to reposition him. Sometimes, that was 20 times in one night." (Father 4)

Feeling Powerless

Sometimes, parents also experience feelings of powerlessness. Parents indicated that they do not know how to help their son/daughter when he/she is struggling to accept their disability and its consequences. Feelings of powerlessness also occur when the child needs medical procedures (e.g., muscle lengthening surgery) which are painful and require a long-term rehabilitation. The experience that they cannot help their child to ameliorate his/her physical and emotional pain is very stressful for parents.

> "When she feels sad about her situation, which has happened before, I cannot change anything about it. I find that difficult, that I can't take it away, change it." (Mother 1)

Accepting the Diagnosis

A fourth important theme that was retained from the interviews concerns the process of accepting the child's diagnosis. These essential experiences could not directly be related to one of the three basic psychological needs and were therefore seen as a separate theme.

All participants indicated that the realization that their child was not developing as expected and the search for the diagnosis was a complex and emotional process. Parents indicated that the acceptance process of the condition and acclimatizing to its consequences could only start after the diagnosis was finally made. Parents said that they had to adjust their expectations about their child's, their own, and their family's lives. They needed to come to terms with the possible consequences of the condition and were confronted with many uncertainties about the future. The extent to which parents are able to accept the diagnosis has a big impact on their personal well-being. One parent stated that he was only able to live his life again and to look forward after he had accepted his son's diagnosis. When the diagnostic process took a long time or was very difficult, parents indicated feelings like they were not being heard or not taken seriously. When a formal diagnosis finally was made, these parents also reported a sense of relief to have an explanation for the experienced difficulties.

Because in some cases, the child's brain lesion was a consequence of difficulties during the delivery process, six participants described the birth of their child as a traumatic experience. This led, for some of these participants, to permanent feelings of guilt and failure or to feelings of anger towards the medical staff (when parents felt that the medical staff took the wrong decision during delivery).

> "The thing with cerebral palsy is that you feel guilty. Because I could not get her out, I could not bring her into the world. So, that sticks with you." (Mother 5)

> "The most difficult period that we had was, in my opinion, when we had to accept that our child has a disorder." (Father 6)

The Uncertainty About the Future

A final important theme that parents mentioned concerns the uncertainty about the future. All participants expressed to be worried about their adolescent's future. Important sources of uncertainty concern the adolescent's future professional career and the continuity of care when parents are no longer around to help him/her. Currently, all adolescents were still in primary or secondary school, but all parents worried about what will happen when their adolescent finishes school. In addition, parents worried about who will manage their child's health care and who will support their child when they pass away. Questions like "Will my child be able to work? Will he or she receive financial support? Will my child be able to live independently, or will I have to take care of him/her forever? How can I guarantee that my child will receive support when I am not longer here to help him/her?" were expressed by all parents.

In order to deal with these uncertainties, some parents try to inform themselves as much as possible about possibilities for future support and financial help. However, this is not sufficient to answer parents' questions and to take away the uncertainty. Other parents try not to think about the future and focus on living in the moment.

> "Now he is in a good place for years and then it will stop. School stops at some point. And then, what will he do then? Where will he go to? Where will he stay? Will he be taken care of when we are not here anymore? A lot of questions…" (Mother 3)

> "I worry about what he will be able to do. He follows an occupational education, which is very good. But if you see how difficult it is for the "able people", how fast everything has to go… That scares me." (Mother 8)

Discussion

Although research has clearly established that parents of children and adolescents with CP are at risk to experience lower levels of well-being and more psychosocial difficulties (definitely when comparing them to parents of typically developing children) (Brehaut et al. 2004; Guyard et al. 2017; Parkes et al. 2011; Pousada et al. 2013), more qualitative research is needed to obtain an in-depth insight in these parents' positive and negative experiences. In order to advance this insight, this qualitative study relied on the SDT (Deci and Ryan 2000), and more specifically on the three basic psychological needs, as a framework to structure these parents' experiences. Through the exploration of parents' need-related experiences, we were not only able to identify risks for need frustration but also to capture opportunities for need satisfaction. In addition to the three need-related themes, we also retained two themes (i.e., 'accepting the diagnosis' and 'the uncertainty about the future') that were not directly related to the three psychological needs, but that were important to capture parents' experiences of raising an adolescent with CP. As the five themes identify important targets for parent support, practical implications will be considered throughout the discussion.

Parents' Need-Related Experiences in the Context of Raising an Adolescent with CP

By integrating both negative and positive experiences within the framework of the three basic psychological needs, this study offers a nuanced insight in parents' wide variety of experiences related to the parenting of their adolescent with CP. In general, parents' experiences indicate that raising a child with CP brings about fundamental changes in parents' freedom; professional careers; relationships with their partner, family, friends; and their own feelings of self-efficacy. Clearly, the impact of raising a child with CP goes beyond parents' parenting role but also transforms their identity more generally.

A first important theme concerns challenges for *parents' need for autonomy*. The findings that parents have little time for their own personal interests and feel like they need to give up a lot in order to support their son or daughter with CP are in line with findings from previous studies. Majnemer et al. (2012), for example, reported that about half of the parents of children and adolescents with CP (aged between 6 and 12 years) experience high levels of stress which negatively impacts their time and emotional state. Parents' difficulties to combine the care for their child with a professional career also corroborate findings from previous qualitative studies (Brehaut et al. 2004). These limitations to pursue a professional career were only reported by mothers and not by fathers, which is in line with research reporting that—on average—mothers spend more time in caregiving tasks than fathers (Byrne et al. 2010). Although some mothers expressed regrets about giving up their career or altering their professional ambitions, other mothers stressed the positive effects of this decision (such as having more time to spend with their son/daughter, increased happiness for both the adolescent with CP and the other family members).

Based on parents' experiences, we can attribute the limitations in parents' personal freedom and their professional career to the intense and time-consuming care tasks (e.g., bringing the child to therapy), practical difficulties, and the fact that (almost) nobody else can take over the care tasks. This might also explain why these autonomy-frustrating experiences continue to be present, even when children reach adolescence. In mainstream populations, adolescents usually become more self-reliant and autonomous, increasing parents' opportunities to invest more in own interests, friends, and work (Galambos and Costigan 2003). Because children with CP often need lifelong support and have less opportunities to participate in typical adolescent activities, this "revival of freedom" does not seem to be present among parents of adolescents with CP (Burkhard 2013; Michelsen et al. 2014). Because frustration of their own need for autonomy has been linked with negative affect, depressive symptoms, and feelings of exhaustion (Bartholomew et al. 2011), it is crucial that these parents receive support to deal with these challenges. For instance, by organizing CP-specific respite care or after-school care, parents would be able to invest more in their personal interests/hobbies or have chances to pursue professional opportunities. It is remarkable that, in this study, we found a total absence of parent-reported need-satisfying experiences concerning their need for autonomy (whereas they did report need satisfaction concerning relatedness and competence). Future research should further explore possibilities to strengthen autonomy-satisfying experiences among these parents.

A second important theme concerned both challenges and opportunities for *parents' need for relatedness*. Based on the current results, we can describe the relationship between parents and their adolescent with CP as close and intense, but also as strenuous and exhausting. Due to the care tasks and the required adaptations, parents are highly involved in the life of their adolescent with CP. That is, adolescents with CP depend strongly on the emotional and practical support of their parents which fosters the relatedness between them. Parents often have a good understanding of their son's or daughter's feelings, thoughts, desires, and intentions. These positive findings are in line with the study of Björquist et al. (2015) showing that parents appreciate having a close relationship with their adolescent with CP and realize that other parents often spend less time with their adolescent. Although this close relationship can result in satisfaction of parents' need for relatedness with their son or daughter, it can also put additional pressure on parents. That is, parents can feel so indispensable for their adolescent's well-being that they experience a loss of their own individuality and feel like they are fused together with their son or daughter, which can lead to feelings of exhaustion and overprotective behavior (Hamilton et al. 2015; Ho et al. 2008; Jankowska et al. 2015; Pelchat et al. 2009).

Parents' relatedness-related experiences did not only concern their relationship with the adolescent with CP but also with their other children, their partner, friends, and family. The finding that the intense care for a child with CP poses threats for parents' relationships with their other children corroborates research among other chronic conditions (Mulroy et al. 2007; Waite-Jones and Madill 2008). Because parents find it important that their other children can pursue their own interests and receive personal attention, they organize special activities or split up the family for doing certain activities with the siblings. These findings corroborate studies on siblings of children with a disability showing that siblings express a need for private time with their parents (Moyson and Roeyers 2012).

Moreover, parents' need-satisfying experiences concerning their relationship with their partner are in line with other studies indicating that—in some families—raising a child with CP strengthens parents' relationship because parents work together as a team to provide the best care for their child with CP (Björquist et al. 2015). The current study also showed that the partner often is the only one who really understands the difficulties and challenges that the family experiences, causing parents to turn more to each other for emotional support. However, raising a child with CP can, at least for some parents, also have a negative impact on the relatedness between parents. Parents indicate that the intense healthcare and the necessity to split up the family to do activities limit the time spent together, which can hamper parents' relationship. In order to interpret the current findings concerning the relatedness between parents, we need to take into account that some interviews were conducted with couples and other interviews with mothers alone. The interviewed couples did not mention any need-frustrating experiences affecting their partner relationship, whereas some mothers who were interviewed alone did mention need-frustrating experiences, such as the effects of splitting up the family. It is possible that parents who participated as a couple were less willing to discuss challenges for their relatedness with the interviewer, whereas mothers who participated alone might have felt more freedom to discuss challenges concerning the relationship with their partner. Another explanation for this finding is that parents whose relationships are not deeply affected by raising a child with CP might have been more willing to participate as a couple than parents who were experiencing more challenges in their relationship. As positive family relationships are a crucial protective factor for the well-being in families of children with CP (Guyard et al. 2017), it is important for support providers to pay adequate attention to the relationships among all family members.

Raising a child with CP does not only affect the relatedness within the family, but also the relatedness with other relatives and friends. The need-satisfying experiences indicate that perceiving support or understanding from the broader network is essential for parents' feelings of relatedness with relatives, friends, and other parents of children with CP. The relationships that develop, continue to exist, or even strengthen in times when parents are experiencing challenges related to their child with CP (e.g., after receiving the diagnosis, when choosing a suitable school), actually become more meaningful and valuable for parents and clearly satisfy parents' need for relatedness. The many reported need-frustrating experiences, however, indicate that raising a child with CP can also put pressure on relationships with the broader network. Parents attribute this to practical difficulties and a lack of energy which affect the amount of time that they can spend with friends. Parents' relationships with relatives and friends are hampered when parents feel misunderstood by their environment or even feel socially excluded. These need-frustrating experiences mesh with studies reporting unsupportive interactions and social isolation and seclusion among parents of children with CP (Alaee et al. 2015; Florian and Findler 2001). This finding in combination with the finding that having a supportive network and social support are important determinants of parents' well-being (Pousada et al. 2013) highlights the importance and the potential of targeting relatedness during counseling. In order to increase comprehension from the broader network, health care providers could, for instance, help parents to inform relatives and friends about their experiences. Another way to support parents' need for relatedness might be by bringing parents in contact with other parents of children with CP.

Finally, parents also discussed the relationships they built towards healthcare providers. Parents reported that the relatedness with health care providers is strongly affected by the attitude of healthcare providers. By being genuinely motivated to improve the child's and family's well-being and by taking a positive and solution-oriented approach to do this, healthcare providers strengthen their relationship with parents. These findings corroborate the determinants for parents' satisfaction with health care that were recently described by Molinaro et al. (2017) in their study about family-centered care for families with CP: parents need (1) a respectful and supportive attitude of health care providers, (2) a balanced partnership in care (i.e., parents are recognized as experts and are actively involved in decision making), and (3) access to correct and comprehensible information.

In sum, relatedness appears to be a very salient theme within parent's experiences while raising a child with CP. Although we found that some relationships might actually be strengthened by raising a child with CP, parents' need for relatedness remains vulnerable. Furthermore, healthcare providers should not only be aware of the relatedness between them and the parents, but should also pay attention to the quality of parents' relationships within (i.e., with partner, siblings) and outside the family (i.e., friends, relatives).

A third important theme concerns parents' *feelings of competence*. Within this theme, we identified a subtheme that concerned need-satisfying experiences, "achieving the unexpected," and two subthemes that concerned need-frustrating experiences, "feeling exhausted" and "feeling powerless." Parents' feelings of competence and self-efficacy are clearly strengthened when they notice that their efforts are improving their child's functioning or well-being. When parents have had these competence-satisfying experiences in the past, it helps them to persevere during more difficult periods and gives them hope that, with time and patience, their efforts will help to reach their goal. This finding corroborates research identifying self-efficacy and feelings of competence as important determinants of parents' mental health and functioning among parents of children and adolescents with CP (Jankowska et al. 2015; Pousada et al. 2013). This suggests that identifying and acknowledging signals of improvements might strengthen parents' feelings of competence and might help them to persevere or to keep up all their efforts.

The current results also show, however, that providing the intense emotional and physical care can really drain parents' energy or can even make them feel like they are not able to offer the required support. Based on these results, it seems that it is the combination of offering practical and emotional support and the very intense character of this support that can cause feelings of physical and/or emotional exhaustion in parents. This finding meshes with the study of Guyard et al. (2017) which shows that respite care is an important environmental factor that is related with lower levels of parental distress. Investing in respite care or in organized at-home support for families with children and adolescents with CP might be a way to support parents' feelings of competence and to avoid that they feel overcharged (Guyard et al. 2017). Feelings of powerlessness were mainly reported in reference to medical procedures and the rehabilitation process afterwards. The finding that the period of a surgery and the recovery is very hard for parents is in line with findings of Whittingham et al. (2013) and stress the importance of qualitative support during this period. Parents indicated that they would be better able to deal with the process of the surgery and the recovery if they would receive more and specific information and if they would have access to practical (at-home) support. In sum, parents' need for competence might be challenged by the emotional and practical care that they need to provide, especially when the child needs a medical procedure or surgery. Nevertheless, noticing that their efforts help their son or daughter to achieve the unexpected fosters parents' feelings of efficacy and gives them energy to persevere.

Taken together, the framework of the three basic psychological needs allowed for an in-depth understanding of parents' positive and negative experiences. The most salient theme was the theme concerning parents' need for relatedness. Raising a child with CP clearly creates diverse opportunities for close relationships but also entails multiple threats for loneliness or social exclusion. Concerning parents' need for autonomy, we could not identify need-satisfying experiences. The finding that parents' feelings of volitional functioning are put under a lot of pressure due to practical issues definitely needs to be taken into account during counseling or when promoting psychosocial outcomes in this population. Finally, parents' need for competence can be threatened when the emotional and practical care exhausts them or when they feel like they are not able to help their child. Beatings the odds and achieving unexpected goals, on the other hand, can boost parents' feelings of competence.

The Importance of Accepting the Diagnosis

In addition to the three need-related themes, we also identified the acceptance of the diagnosis as an essential part of parents' experiences of raising a child with CP. Parents indicated, in line with previous research, that coming to terms with the fact that their child is affected by a permanent disorder is a difficult yet important process (Marvin and Pianta 1996; Pelchat et al. 2009). Parents' acceptance of the diagnosis is often examined during a child's infancy because this is the time when the acceptance process starts (e.g., Rentinck et al. 2009). The current findings, however, indicate that this is a long-term process that strongly impacts on parents' personal well-being. Adolescence might be a developmental phase in which parents are confronted with new feelings of grief because parents need (once more) to let go of certain expectations about their son/daughter (e.g., living independently is not evident) and themselves (e.g., care tasks are not diminishing).

Although this process of accepting the diagnosis could not be structured within the framework of the three basic psychological needs, it does relate with another concept that is central to SDT, that is, the process of internalization (i.e., the process through which values, beliefs, commitments, and behaviors of a person become personally endorsed, align with the self, and reflect own preferences and sensibilities) (Ryan and Deci 2003; Soenens and Vansteenkiste 2011). This process allows people to identify more strongly with their commitments and wholeheartedly endorse them. Thus, the process of internalization might allow parents to experience their identity as a parent of a child with CP as meaningful and a reflection of who they are (i.e., identification) or integrate this identity with other values and goals (i.e., integration) (Ryan and Deci 2003; Soenens and Vansteenkiste 2011). By accepting the child's diagnosis, parents might simultaneously accept their identity as a parent of a child with CP more (i.e., recognizing the meaningfulness and relevance of the identity) and align this identity within their self (i.e., the identity is also aligned with other life values and goals). Given that the extent to which people have internalized their identity affects their need-related experiences, with people who fully endorse their identity having more need-satisfying experiences (Ryan and Deci 2017), it seems plausible that the degree to which parents accept their child's CP diagnosis also influences their psychological needs. More specifically, because parents who accept the diagnosis might have more eye for child's positive characteristics, they might, consequently, experience more volition, reciprocal care, and competence when interacting with their child. By contrast, parents who struggle with the acceptation of their child's diagnosis might focus more on the negative aspects of their child's disability or might appraise challenges encountered during the parenting process as a threat to their own psychological needs, rendering them more vulnerable to experience need frustration when interacting with their child. This hypothesis is supported by findings indicating that parents who have more difficulties to accept the diagnosis (i.e., unresolved parents) focus more on the negative aspects of their child's disability and consequently experience more stress (Marvin and Pianta 1996; Sheeran et al. 1997). In addition to parents' acceptance affecting need-related experiences, it is also possible that parents' psychological needs facilitate or hinder the acceptance process. That is, parents' acceptance process might be supported when parents experience feelings of volition, reciprocal care, and self-efficacy within their parenting role whereas experiences of need frustration might hamper this process of acceptance. Given that parents' acceptance of their child's diagnosis plays a central role in parents' experiences, an important task for future research is to disentangle the associations between parents' resolution of their child's diagnosis and their psychological needs. In order to examine the associations between parents' acceptance of the diagnosis and their need-related experiences more in-depth, future research could conduct questionnaire (including, for instance, the Reaction to Diagnosis Interview (Marvin and Pianta 1996)) or mixed-method studies probing deeper cognitions or attributions of parents.

In line with studies reporting that parents of children with CP can experience feelings of guilt (irrespectively of the real cause of the disability) (Findler et al. 2016; Francis 2012; Huang et al. 2010), we also found that some mothers expressed feeling guilty. Although guilt is not directly related with parents' psychological needs, it is possible that feelings of guilt affect parents' need-related experiences. For instance, a parent who feels guilty about their child's disability might focus excessively on taking care of his/her child and, as a consequence, might choose to invest less in personal hobbies or social relationships, hence exacerbating frustration of his/her need for autonomy and relatedness (Pelchat et al. 2009). Parents might also think that they will never be able to make up for their child's difficulties and, thus, feel like a failure as a parent (i.e., competence frustration). Given that feelings of guilt might contribute to less happiness and more pressure among parents (Findler et al. 2016; Ryan and Deci 2017), which in turn can affect how parents interact with their child (Ryan and Deci 2017), it is important that healthcare providers are aware of and pay attention to feelings of guilt among parents of adolescents with CP.

What Is Lying Ahead? The Impact of the Uncertainty About the Future

The finding that all participating parents felt worried about the future of their son or daughter is in line with other qualitative studies examining parents' personal experiences in the context of CP (Alaee et al. 2015; Björquist et al. 2015; Whittingham et al. 2013). One of the most important worries related to what would happen when the parents themselves or no longer able to support or help their son/daughter or when they pass away. In line with previous findings (Alaee et al. 2015), parents do not assume or do not wish that siblings or other family members take over the care of their child. In the current study, parents also expressed a lot of worries and uncertainty about the services and financial aid that will be available once their child finishes secondary school. This is in line with the finding of Palisano et al. (2009) that 50% of the parents of a child with a disability ask for more information about current or future available services. Parents try to deal with these worries by seeking for information, but often a lot of their questions remain unanswered. In order to help parents in this search for answers, healthcare providers should inquire parents (and other family members) not only about acute problems or worries but also about more long-term worries or hypothetical problems. As parents' worries might change throughout the development of the child, it is important to organize a support- or healthcare system that offers guidance or counseling throughout each developmental phase of the child's life.

Limitations and Directions for Future Research

A first limitation is that the majority of the participants were mothers and that only three fathers participated together with the mother. It might be interesting to interview mothers and fathers separately in order to better examine differences and similarities in their experiences of raising a child with a disability (Van Hove et al. 2017). In addition, the current study included both single-parent interviews and dyad-interviews. It is possible that this influenced the discussion or presence of certain themes, such as the relatedness between partners. It might be, for instance, that parents with a strong partner relationship are more willingly to participate together in the interview whereas parents who experience more difficulties might prefer to participate alone. For future research, it would be interesting to include more dyads and to examine differences in need-related experiences between single-parent interviews and dyad-interviews.

A second limitation concerns the limited sample that was conducted within a specific region (i.e., Flanders, Belgium). Because parents' experiences possibly depended upon regional available support, their experiences might differ from parents living in other regions. Nevertheless, the results do show clear similarities with studies from other countries, which indicates that many experiences are shared across regions, at least in Western countries.

Other demographic characteristics of the participating parents and their children might also impact the generalizability of this study. Current results might, for instance, be affected by the fact that most children of the current sample had higher levels of functional ability (i.e., eight children had a GMFCS level I or II and one child with level V). Future research should examine more in-depth whether parents' need-related experiences, their acceptance of the diagnosis and their worries relate with disability severity by recruiting a more heterogeneous sample or by focusing on specific subsamples.

Another demographic characteristic that might limit the generalizability of the findings is the focus on parents of adolescents. This study focuses on this developmental stage because it brings about specific tasks, challenges, and opportunities for both the adolescent with CP and his/her parent (Burkhard 2013; Majnemer et al. 2015; Rapp et al. 2017), which might affect parents' need-related experiences. For instance, by the time their child reaches adolescence, parents have gained a lot of experience and developed a variety of new skills, increasing opportunities for competence satisfaction (Ribeiro et al. 2016). This might explain why parents reported fewer competence-related experiences in comparison to autonomy- and relatedness experiences. It might be interesting to examine whether parents' competence-related experiences change throughout the development of the child. On the other hand, the physical, emotional, and social changes that are typical for adolescence—in both children with and without CP—might require new adaptations from parents, which can pose threats for their experiences of need satisfaction (Collins and Laursen 2004; Hamilton et al. 2015; Magill-Evans et al. 2001). During this developmental phase it might be, for instance, difficult for parents of adolescents with special needs to offer their son or daughter more autonomy because they are used to being needed and relied upon (Hamilton et al. 2015). Adolescence has also been shown to be a period in which parents can experience more feelings of grief because they realize that their son or daughter is less independent than other adolescents or because certain milestones will not be reached (e.g., going to university) (Hamilton et al. 2015).

Finally, these qualitative findings do not allow to draw conclusions about relations between the identified themes. It might, for instance, be interesting for future research to examine more in-depth how the satisfaction or frustration of these parents' needs interact with each other. According to SDT, the three psychological needs are distinct, yet they are intertwined with each other. That is, when one of the three needs is satisfied (or, in contrast, frustrated), this often goes together with the satisfaction (or frustration) of the other two needs (Chen et al. 2015; Ryan and Deci 2017). Thus, it seems plausible that parents who experience high levels of psychological freedom, will also experience higher levels of relatedness and competence. Future research would also do well to examine the associations between parents' reaction to the diagnosis, the degree to which parents worry about their child's future and their need-related experiences. Parents who experience high levels of need satisfaction might, for instance, worry less about their child's future and find it easier to accept their child's diagnosis. Conversely, it is also possible that the degree to which parents worry about their child's future and parents' resolution concerning their child's diagnosis affect parents' need-related experiences (e.g., parents who worry excessively might experience less need satisfaction in their parenting role). In order to examine these (potentially reciprocal) relationships, prospective longitudinal studies are needed, combining more quantitative methods (e.g., observations, standardized questionnaires) as well as more in-depth qualitative methods (e.g., into more underlying motives and feelings).

In sum, by relying on the three basic psychological needs, as described by the SDT, this qualitative study offered an in-depth insight into the complex experiences of parents of adolescents with CP. Although raising an adolescent with CP entails threats for parents' freedom, professional career, personal relationships, and their feelings of self-efficacy, it can—at the same time—also offer opportunities to feel closely connected with others (including the experience of a valued, special relationship with the child with CP) and to feel effective when the unexpected can be achieved together. In addition to these need-frustrating and need-supportive experiences, parents' acceptance of the diagnosis and parents' worries about their child's future are also essential themes to take into account as keys to provide better parent support.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethics Statement The study received ethical approval from the Institutional Review Board of Ghent University, the Ethical commission of the Faculty of Psychology and Educational Sciences.

Informed Consent Informed consent was obtained from all participants in this study.

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