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Parents' Need-Related Experiences When Raising an Adolescent With Cerebral Palsy: "I am partially her shadow" --Manuscript Draft--

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Abstract:	<p>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. Therefore, 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 cerebral palsy.</p> <p>Nine parents of adolescents with cerebral palsy, 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. 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.</p> <p>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.</p>				
Corresponding Author:	Lisa M. Dieleman Universiteit Gent BELGIUM				
Corresponding Author Secondary Information:					
Corresponding Author's Institution:	Universiteit Gent				
Corresponding Author's Secondary Institution:					
First Author:	Lisa M. Dieleman				
First Author Secondary Information:					
Order of Authors:	<table border="1"> <tr> <td>Lisa M. Dieleman</td> </tr> <tr> <td>Roos Van Vlaenderen</td> </tr> <tr> <td>Peter Prinzie</td> </tr> <tr> <td>Sarah De Pauw</td> </tr> </table>	Lisa M. Dieleman	Roos Van Vlaenderen	Peter Prinzie	Sarah De Pauw
Lisa M. Dieleman					
Roos Van Vlaenderen					
Peter Prinzie					
Sarah De Pauw					
Order of Authors Secondary Information:					
Author Comments:	<p>Dear Editor,</p> <p>Hereby we would like to submit our manuscript entitled: 'Parents' Need-Related Experiences When Raising an Adolescent With Cerebral Palsy: "I am partially her shadow" '. This paper reports qualitative findings regarding parents' own perspectives</p>				

	<p>on their experiences in the context of raising an adolescent with Cerebral Palsy (CP). Although an abundance of research shows that parents of children with CP are at risk for experiencing decreased levels of well-being, this type of research conveys only limited understanding of the specific experiences of parenting an adolescent with CP. Therefore, this qualitative study aimed to advance insights into parents' need-related experiences. We were particularly interested in parents' experiences relevant to the psychological needs for autonomy, relatedness, and competence because research based on Self-Determination Theory (SDT), a motivational theory prominent in current research on parenting, suggests that these need-related experiences play an essential role in parents' well-being. In order to get an in-depth insight into parents' experiences, nine parents of children with CP, aged 10 to 18, participated in an interview concerning their experiences in raising an adolescent with CP.</p> <p>We would like to note that none of the analyses or findings reported in this paper have been reported in prior work and that this paper is not being simultaneously submitted elsewhere.</p> <p>We look forward to receiving the reviewers' comments. Yours sincerely, Lisa Dieleman (corresponding author), Roos Van Vlaenderen, Peter Prinzie, and Sarah De Pauw.</p> <p>Lisa Dieleman Ghent University, Department of Developmental, Personality and Social Psychology Henri Dunantlaan 2, 9000 Gent, Belgium Tel: +32 09 264 64 15 Lisa.Dieleman@UGent.be</p>
<p>Suggested Reviewers:</p>	<p>Petra Boström petra.bostrom@psy.gu.se Petra Boström works on the impact of children with a disability on parents and also applies qualitative methods to do so.</p> <p>Annette Majnemer annette.majnemer@mcgill.ca Dr. Majnemer's research interests focus on the developmental, functional and quality of life outcomes of children with disabilities, including children with cerebral palsy. She also examines distress among parents of children with cerebral palsy.</p> <p>Elisabet Björquist elisabet.bjorquist@med.lu.se Elisabet Björquist does research about parents' experiences of adolescents and early adults with cerebral palsy.</p> <p>Elise Davis eda@unimelb.edu.au The research of Dr. Davis focuses on the quality of life of parents and children with a disability, including children with cerebral palsy.</p> <p>Koa Whittingham koawhittingham@uq.edu.au Dr. Whittingham examines parenting among children with a neurodevelopmental disability, including children with cerebral palsy. In order to get an in-depth understanding of parents' challenges, she also used qualitative methodologies.</p>

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1 **Parents' Need-Related Experiences When Raising an Adolescent With Cerebral Palsy:**

2 *“I am partially her shadow”*

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

11 Nine parents of adolescents with cerebral palsy, aged 10 to 18 years, participated in an
12 in-depth interview concerning their need-related experiences in raising their son or daughter
13 with CP. The data were analyzed with deductive thematic analysis. Parents' experiences were
14 classified into five themes and nine subthemes. Next to the need-related themes, the themes
15 'accepting the diagnosis' and 'uncertainty about the future' were also identified as essential
16 to capture parents' experiences.

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

22
23 **KEY WORDS:** Cerebral Palsy, Parenting, Need-related Experiences, Self-Determination
24 Theory, Qualitative Research

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26 Cerebral palsy (CP) is a chronic neuro-developmental disorder, due to a non-
27 progressive brain lesion, causing motor disability (Odding, Roebroek, & Stam, 2006).
28 Children with CP experience dysfunctions in their muscle tone, movement or posture which
29 cause activity limitations. Due to differences in the size, type, and location of the brain lesion
30 there is a lot of variety in the severity and type of dysfunctions that children experience
31 (Rosenbaum, Paneth, Levinton, Goldstein, & Bax, 2007). In addition, these children often
32 experience comorbid physical, cognitive and social-emotional impairments, such as epilepsy,
33 intellectual disability, and peer problems (Rosenbaum et al., 2007). As a consequence,
34 parents are faced with insecurity about the child's development, they have to consult medical
35 experts on a regular basis, organize specific healthcare, and make practical adaptations to
36 their daily life. Parents might also need to adapt their expectations with regard to their parent-
37 role, learn specialized caregiving behaviors, and re-organize their family life (Pousada et al.,
38 2013). These adaptations and efforts can seriously affect parents' physical and mental health
39 or well-being. Research has convincingly shown that parents of children and adolescents with
40 CP – as a group – are at risk for decreased levels of well-being and increased psychosocial
41 difficulties, such as stress, depressive feelings, and anxiety, compared to parents of typically
42 developing children (Brehaut et al., 2004; Guyard, Michelsen, Arnaud, & Fauconnier, 2017;
43 Parkes, Caravale, Marcelli, Franco, & Colver, 2011; Pousada et al., 2013). Yet, not all
44 parents of children with CP experience mental health problems or high levels of stress
45 (Pousada et al., 2013). This variation in the well- or ill-being of parents of children with CP
46 has been linked with child (e.g., the presence of comorbid problems) and parent
47 characteristics (e.g., parents' self-efficacy) and contextual factors (e.g., social support)
48 (Majnemer, Shevell, Law, Poulin, & Rosenbaum, 2012; Manuel, Naughton, Balkrishnan,
49 Paterson, & Koman, 2003; Guyard et al., 2017; Pousada et al., 2013; Raina et al., 2005).

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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. Therefore, this qualitative study aims to advance the understanding of parents' experiences when raising a child with CP by considering their experiences through the lens of Self-Determination Theory (SDT) (Deci & Ryan, 2000), a macro-theory on human socialization. More specifically, the three basic psychological needs, which represent the heart of the SDT, are put forward as a structuring framework to better understand parents' wide variety of positive and negative experiences.

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**The basic psychological needs for autonomy, relatedness and competence among
parents of adolescents with CP**

According to the SDT, every human being has three basic psychological needs: 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 & 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 and happiness, whereas need-frustration makes people vulnerable for ill-being, passivity, and psychopathology (Deci & 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

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75 can be interpreted as challenges for need-satisfaction or even risks for need-thwarting. For
76 instance, many parents of children and adolescents with CP need to give up or change their
77 professional career, which could be interpreted as a threat for their need for autonomy
78 (Brehaut et al., 2004). Parents also experience a lot of restrictions to develop their own
79 interests in their daily life due to the constant care they need to provide and the lack of people
80 who can provide temporary care (Alaee, Shahboulaghi, Khankeh, & Kermanshahi, 2015). In
81 addition, parents report limited time to spend as a couple and indicate that raising a child with
82 CP places strains on their relationship, findings that could indicate threats for parents' need
83 for relatedness (Alaee et al., 2015; Davis et al., 2009; Florian & Findler, 2001). Parents of
84 children and adolescents with CP have also reported to feel lonely and to lack social contacts
85 because the intense healthcare and practical difficulties limit their possibilities to join
86 activities with friends or families or because their life has changed so much that it becomes
87 difficult to connect with friends (Alaee et al., 2015; Davis et al., 2009). Threats for parents'
88 need for competence can be found in parents' reports of difficulties when providing
89 specialized care and organizing medical care or when interpreting child behavior and
90 responding in an adaptive way (Huang, Kellet, & St John, 2012; Whittingham, Wee, Sanders,
91 & Boyd, 2011).

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92 In addition, the SDT framework allows to identify and structure possibilities for need-
93 satisfaction. Although positive experiences have been addressed less in both quantitative and
94 qualitative research among parents of children with CP, and children with developmental
95 disabilities in general (Hastings & Taunt, 2002), some findings do suggest opportunities for
96 need-satisfying experiences. Parents reported, for instance, that having a son or daughter with
97 CP resulted in a new social network, which can be interpreted as satisfaction of their need for
98 relatedness (Davis et al., 2009). The finding that some families report strong family cohesion
99 and close relationships also suggests possibilities for a parent's relatedness satisfaction

100 (Björquist, Nordmark, & Hallström, 2015; Fiss et al., 2013). Parents' feelings of competence
101 might also be satisfied when their child or adolescent reaches a goal or when they notice that
102 the specialized healthcare they organize or the exercises that they do at home are paying off
103 (Davis et al., 2009).

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

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

125 autonomy, relatedness, and competence. This study focuses on parents of adolescents because
126 this developmental stage brings about specific tasks, challenges, and opportunities for both
127 the adolescent with CP and his/her parent (Burkhard, 2013; Majnemer, Shikako-Thomas,
128 Schmitz, Shevell, & Lach, 2015; Rapp et al., 2017), which might affect parents' need-related
129 experiences. For instance, by the time their child reaches adolescence, parents have gained a
130 lot of experience and developed a variety of new skills, increasing opportunities for
131 competence satisfaction (Ribeiro, Vandenberghe, Prudente, Vila, & Porto, 2016). On the
132 other hand, the physical, emotional and social changes that are typical for adolescence – in
133 both children with and without CP- might require new adaptations from parents, which can
134 pose threats for their experiences of need-satisfaction (Collins & Laursen, 2004, Hamilton,
135 Mazzucchelli, & Sanders, 2015; Magill-Evans, Darrah, Pain, Adkins, & Kratochvil, 2001).
136 During this developmental phase it might be, for instance, difficult for parents of adolescents
137 with special needs to offer their son or daughter more autonomy because they are used to
138 being needed and relied upon (Hamilton et al., 2015). Adolescence has also been shown to be
139 a period in which parents can experience more feelings of grief because they realize that their
140 son or daughter is less independent than other adolescents or because certain milestones will
141 not be reached (e.g., going to university) (Hamilton et al., 2015).

142 **Method**

143 *Procedure and Participants*

144 This qualitative study is part of a large, on-going, longitudinal study on parents of
145 children with cerebral palsy. Parents were first recruited in 2015 through seven Belgian
146 service centers for children with physical disabilities. Initially, 135 parents were recruited to
147 participate in this broad quantitative study. During the follow-up study, one year later, parents
148 were asked if they would like to be contacted to participate in an interview about their

149 experiences as a parent. In total, 78 parents indicated that they would like to be contacted for
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3 150 this interview.

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5 151 In order to participate in the interview, families had to meet two inclusion criteria: the
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7 152 child (1) had received a diagnosis of cerebral palsy, (2) was aged between ten and eighteen
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10 153 years and (3) his/her principal residency was at home with the parent(s). Parents could choose
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12 154 to participate alone or as a couple. In total, 18 parents who met these criteria were randomly
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14 155 selected and contacted to participate in the interview. The final data sample consisted of ten
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16 156 interviews conducted with seven mothers and three couples. One interview was strongly
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18 157 affected by the mothers' psychiatric disorder and because we did not receive answers to the
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20 158 questions, this interview was not included in further analysis. The final sample, thus,
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22 159 comprised 9 interviews with six mothers and three couples. All adolescents were diagnosed
23
24 160 with spastic CP and were living at home. One adolescent (case 3) spent one night per week in
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26 161 school. The child's gross motor function was assessed with the Gross Motor Function
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28 162 Classification System Family Report (GMFCS-FR; Palisano, Rosenbaum, Bartlett, &
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30 163 Livingston, 2008). The GMFCS is a classification system that determines the severity of
31
32 164 cerebral palsy on the basis of the child's functional abilities and needs of assistive technology
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34 165 for mobility. The GMFCS identifies five levels with children classified in level I being able
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36 166 to walk without restrictions but having limitations in more advanced motor skills and children
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38 167 classified in level V having very limited motor abilities. The family report of the GMFCS has
39
40 168 been shown to be a reliable method for measuring gross motor function (Morris, Galuppi, &
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42 169 Rosenbaum, 2004). Most adolescents had relatively good functional motor abilities (as
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44 170 indicated by level 1 and 2 on the GMFCS), but one adolescent (case 3) was not able to sit
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46 171 independently and to control his own head or body posture (i.e., level V on the GMFCS). All
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48 172 parents reported comorbid diagnoses (such as epilepsy or autism spectrum disorder). More
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50 173 demographic information is presented in Table 1.
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174 Parents participated in a semi-structured interview focusing on their need-related
175 experiences related to raising a child with CP. Prior to the interview, parents received
176 information about the study and informed consent was obtained from all participants. The
177 study received ethical approval from the organizing university's Institutional Review Board.

178 At the beginning of the interview, the three psychological needs were introduced to
179 parents. Next, parents were asked how raising a child with CP affected their need for
180 autonomy (e.g., *How does raising a child with CP influence your freedom to make your own*
181 *choices?*), relatedness (e.g., *How does raising a child with CP influence your social life?*) and
182 competence (e.g., *Do you feel capable to deal with the challenges that raising a child with*
183 *CP brings about?*). In addition to these three main themes, parents could introduce other
184 topics that they deemed important for their experience. Therefore, the interview schedule was
185 handled flexibly, and individual topics were followed by probes.

186 *Analysis*

187 The interviews were digitally recorded and lasted between 31 and 87 minutes. The
188 verbatim transcripts were analyzed in accordance with the principles of thematic analysis
189 (Braun & Clarke, 2006) using the software program NVivo (QSR International, 2012).
190 Because the three psychological needs described by SDT were used as a framework to
191 structure parents' experiences, the data-analysis relied on deductive thematic analysis (Braun
192 & Clarke, 2006). Nevertheless, because the interview schedule was handled flexibly it was
193 also possible to explore additional themes that are essential to fully capture parents'
194 experiences. The data-analysis consisted of recurrent phases of reading through the
195 interviews, coding the data and creating (sub)themes.

196 First, the second author familiarized herself with the data by reading the interviews
197 several times and noting comments about the meaningful and relevant information in the
198 interview. Next, the first five interviews were coded openly, resulting in an extensive list of

199 initial codes. These initial codes were organized into potential themes and subthemes by the
200 first two authors. After this, the first two authors evaluated whether the codes within a
201 (sub)theme formed a coherent pattern and whether they accurately represented parents’
202 experiences. Less relevant (sub)themes were removed and a final list of (sub)themes was
203 formulated. Finally, each theme was defined and representative quotes were selected.

204 In order to ensure credibility, each participant was presented with the transcribed
205 interview and was given the chance to add information or to comment on the interview. In
206 addition, we ensured credibility through data triangulation (i.e., using multiple researchers for
207 data-analyses). Personal biases in the data-analysis were limited through the group process, in
208 which the different researchers discussed and reflected together upon the list of (sub)themes.

209 **Results**

210 The analyses of parents’ experiences identified five important themes (see Table 2).
211 Three themes could be structured within the framework of the psychological needs and were
212 labeled as challenges for parents’ need for (1) autonomy, (2) relatedness, and (3) competence.
213 The fourth and fifth theme that were retained concerned (4) the process of accepting the
214 diagnosis, and (5) the uncertainty about the future.

215 *Challenges for parents’ need for autonomy*

216 A first important theme within parents’ experiences related to raising a child with CP
217 refers to challenges for parents’ need for autonomy. All participants reported diverse
218 experiences in which their need for autonomy was frustrated. Parents felt that they needed to
219 give up a lot, such as own interests and professional ambitions. These autonomy-frustrating
220 experiences encompass an affective component of regret and sadness (e.g., feeling different
221 from other families) and a more practical component (e.g., re-organizing family routines to
222 adapt to the therapy schedule of the adolescent with CP). Parents indicated that the
223 limitations to their autonomy have short-term and long-term consequences. A short-term

224 consequence, for instance, is that parents feel exhausted and have limited opportunities to
225 relax. A long-term consequence, for example, is the limitation of career opportunities. This
226 theme comprises two specific challenges: (1) experiencing restrictions in daily life and (2)
227 limitations in pursuing an own career.

228 **Experiencing restrictions in life.** The subtheme ‘experiencing restrictions in life’
229 refers to the affective experience to be different from other families and more specifically the
230 feeling to have less opportunities in life than other families, and the regret and sadness about
231 these differences. Parents feel like they have to give up their autonomy because their
232 adolescent needs a lot of support, because the management of the healthcare and the therapies
233 are time-consuming, and because their son or daughter is not able to do certain activities
234 (e.g., go for daytrip with the bike). Although parents indicate that their son or daughter
235 benefits from these adaptations, they experience them at the same time as restrictive. Eight
236 parents indicated that they did not have had time for themselves since their child with CP was
237 born. An important factor that contributes to this feeling of restriction is that parents take full
238 responsibility for the care at home and are not likely to allow someone else to take care of
239 their son or daughter. Parents perceive themselves as the only ones who can provide the best
240 care, or they feel like other people (e.g., family, friends, external babysit) are not willing or
241 are too scared to take care of the child with a disability.

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

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

272 **An intense relationship between parent and child.** Parents experience the
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2 273 relationship with their adolescent with CP on the one hand as more special and precious than
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4 274 with their other children, but at the same time describe it as more strenuous and exhausting.
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7 275 Parents attribute the latter experience to the intense physical and emotional support that their
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9 276 son/daughter needs. Parents feel that their child strongly relies on them and that they are
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11 277 indispensable for their child. The parents stressed that they enjoy giving this extra support but
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13 278 that it is also very tiring and exhausting for them.
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17 279 [Let us say that I am partially her shadow. So, in a way we stick to each other. (Mother
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22 281 [Everybody loves his/her child but this relationship is a lot more special. Yes, it really is
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24 282 very special. Very precious. Also more burdensome. But as mother you do everything for
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26 283 your child. (Mother 3)]
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29 284 **Challenges for relatedness with siblings.** Due to the intense support that adolescents
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31 285 with CP need, parents feel like their relationship with their other children is put under
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33 286 pressure. Parents feel like they (too) often ask siblings to take into account and to adjust
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35 287 themselves to the disability of their brother or sister. Parents often have to refuse their other
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37 288 children to do activities because they are not accessible for the child with CP or because the
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39 289 child with CP is not able to keep up with the activity. In order to allow the siblings to do
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41 290 these activities anyway, families split themselves up and do activities separately. For
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43 291 example, the mother does an activity with the child(ren) without CP, while the father and the
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45 292 child with CP do an activity adapted to the possibilities of the child. This solution, however,
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47 293 gives parents the feeling to be less connected as a family. Other families organize special
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49 294 moments or activities with the sibling because they find it important that the sibling also
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51 295 receives personal attention.
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5 296 [Always split up. Yes, nine out of ten times, we are split up. So our whole family is always
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7 297 split up and X (brother of the child with CP) has been restricted because of that. Since he
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9 298 was a toddler. (Mother 2)]

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12 299 [Y (brother of the child with CP) can sometimes say - while laughing- that everything
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14 300 evolves around A (child with CP). And yes, you do take into account the one child more
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16 301 than the other. (Mother 8)]

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19 302 **Challenges for relatedness with partner.** Parents indicated that raising a child with
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21 303 CP impacted the relationship with their partner, both in a positive and a negative way. In five
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23 304 interviews, parents indicated that their relationship with their partner became more intense
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25 305 due to the disability of their son/daughter. Thanks to the challenges that they face together,
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27 306 parents grow closer together and find ways to support each other. When one partner is feeling
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29 307 exhausted, worried or scared, the other partner increases his/her support and helps the
30
31 308 exhausted partner to persevere and to stay positive and hopeful. The practical difficulties that
32
33 309 come with CP also force parents to collaborate more in order to organize their family life.

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35 310 When parents are able to work as a team and succeed in this organization, they experience a
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37 311 feeling of pride and accomplishment. On the other hand, parents also reported negative
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39 312 effects on the relationship with their partner. Parents especially experienced the fact that they
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41 313 often have to split up the family while doing activities as negative. Parents also feel that they
42
43 314 have little time to do things as a couple and that their relationship is dominated by care tasks.

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46 315 [We were lucky: when the one person felt down, the other was not. And we always have
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48 316 cheered each other up the first two years, constantly. (Mother 4)]

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51 317 [For us, it was positive. We have always supported each other a lot. (Father 6)]

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54 318 [You always have to split up, so you always do everything separate. Yes, I think that drove
55
56 319 us apart. And by the time you realize it, it's too late. (Mother 8)]

320 **Challenges for relatedness with the broader network.** Raising a child with CP also

321 affects parents' relationships with their broader network, including friends and family.

322 Parents shared both positive and negative experiences related to this subtheme. Six

323 participants indicated that their family, and mostly their parents, represent an important

324 source of support. Three participants stated that the presence of CP in their family had no

325 negative impact whatsoever on their social relationships. Friendships that lasted, despite the

326 difficult situation and parent's lack of time, actually become extra meaningful and valuable.

327 Parents highly appreciate acts of support from their friends and family. Parents mentioned,

328 for example, feeling supported when their family visited their child when he/she is

329 hospitalized. Some parents also mentioned that they developed new friendships with other

330 parents of children with disabilities because these parents understand them better and can

331 support them better.

332 Next to these positive experiences, parents also reported multiple experiences of loss.

333 Four participants felt like they had lost a lot of friends due to a lack of time to be with friends,

334 practical issues making it difficult to join activities with other families (e.g., activities that

335 have a mismatch with the motor capacities of their adolescent), and a lack of energy (i.e.,

336 parents feel too tired for social activities). Participants also indicated that, at times, they do

337 not feel understood by their friends and family because they are not able to evaluate the

338 impact of the disability correctly. This lack of understanding can be manifested in negative

339 comments about or in the minimization of the disability, which gives parents the feeling to be

340 all alone. Some families also experience social exclusion in the form of pitying looks,

341 whisperings, laughter, being stared at, and exclusion of their adolescent during certain

342 activities.

343 [We lost a lot of friends. It takes a while, it does not happen from one day to the other.

344 But eventually, by having a child with CP, you experience limitations. You can't go

1 345 everywhere. You can't be on time. And sometimes you can't join. And in the end, you do
2
3 346 lose some friends. But, on the other hand, there are also people with whom you build a
4
5 347 closer relationship. People who understand you very well and even help you. And now
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7 348 that he (i.e., child with CP) is becoming older, he has a lot of friends with CP and we are
8
9 349 also close friends of their parents. We do a lot of things together. So actually, those are
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11 350 new friendships that developed with parents of similar children. And that – not that I don't
12
13 351 like my other friends - has become something very valuable. (Mother 3)]
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17 352 [We have noticed a lot of denial in people. We saw the severity of the situation and we
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19 353 knew it was very serious. And in the beginning my mother mostly minimized it. And that
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21 354 was hard for me. She was like “everything will be fine”. And I did not want to hear that.
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24 355 (Mother 9)]

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27 356 **Challenges for relatedness with healthcare providers.** Families of children with CP
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29 357 have frequent, intense and long-lasting contacts with healthcare providers. The healthcare
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31 358 providers mentioned by the participants include teachers and the management of schools,
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33 359 physiotherapists, occupational therapists, counsellors who offer at-home-support, and doctors
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35 360 and nurses of hospitals. Parents mentioned diverse positive experiences with these healthcare
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37 361 providers. Parents mostly valued healthcare providers who are genuinely interested in the
38
39 362 well-being of their family and child. Parents experience healthcare providers as supportive
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41 363 when they notice and value the strengths of their son/daughter (instead of focusing only on
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43 364 the deficits and impairments). Parents also feel more connected with the healthcare providers
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45 365 when they help to look for solutions if the child is not (yet) able to do something. By doing
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47 366 this, healthcare providers help parents to see possibilities and motivate them to continue
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49 367 offering the intense health care that their son/daughter needs.
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56 368 The relatedness with healthcare providers is undermined, however, when parents feel
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58 369 that healthcare providers underestimate their child's abilities, do not support their child to
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370 improve, and only focus on problems or impairments. A lack of or a negative style of
371 communication also harms the relationship with healthcare providers.

372 [We could not stand that, every time we went to his school they said: “he cannot do this,
373 he cannot do that, ... ”. (Mother 6)]

374 *Challenges for parents’ need for competence*

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

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

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395 [As long as I could support her in the right direction, I felt good. (Mother 1)]

396 [It makes it up for me to see them (i.e., her children with a disability), now that they are
397 older, and I think “wow”. Maybe I didn’t fail (as a mother), after all. (Mother 9)]

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

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

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

419 **Feeling powerless.** Sometimes, parents also experience feelings of powerlessness.
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2 420 Parents indicated that they do not know how to help their son/daughter when he/she is
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5 421 struggling to accept their disability and its consequences. Feelings of powerlessness also
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7 422 occur when the child needs medical procedures (e.g., muscle lengthening surgery) which are
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10 423 painful and require a long-term rehabilitation. The experience that they cannot help their
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12 424 child to ameliorate his/her physical and emotional pain is very stressful for parents.
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14 425 [When she feels sad about her situation, which has happened before, I cannot change
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17 426 anything about it. I find that difficult, that I can't take it away, change it. (Mother 1)]
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19 427 *Accepting the diagnosis*

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22 428 A fourth important theme that was retained from the interviews concerns the process of
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24 429 accepting the child's diagnosis. These essential experiences could not directly be related to
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27 430 one of the three basic psychological needs and were therefore seen as a separate theme.
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29 431 All participants indicated that the realization that their child was not developing as
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32 432 expected and the search for the diagnosis was a complex and emotional process. Parents
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34 433 indicated that the acceptance process of the condition and acclimatizing to its consequences
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36 434 could only start after the diagnosis was finally made. Parents said that they had to adjust their
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39 435 expectations about their child's, their own, and their family's lives. They needed to come to
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41 436 terms with the possible consequences of the condition and were confronted with many
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44 437 uncertainties about the future. The extent to which parents are able to accept the diagnosis has
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46 438 a big impact on their personal well-being. One parent stated that he was only able to live his
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49 439 life again and to look forward after he had accepted his son's diagnosis. When the diagnostic
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51 440 process took a long time or was very difficult, parents indicated feelings like they were not
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54 441 being heard or not taken seriously. When a formal diagnosis finally was made, these parents
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56 442 also reported a sense of relief to have an explanation for the experienced difficulties.
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443 Because in some cases the child's brain lesion was a consequence of difficulties during
444 the delivery process, six participants described the birth of their child as a traumatic
445 experience. This led, for some of these participants, to permanent feelings of guilt and failure
446 or to feelings of anger towards the medical staff (when parents felt that the medical staff took
447 the wrong decision during delivery).

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

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

452 *The uncertainty about the future*

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

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

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

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

474 475 **Discussion**

476 Although research has clearly established that parents of children and adolescents with
477 CP are at risk to experience lower levels of well-being and more psychosocial difficulties
478 (definitely when comparing them to parents of typically developing children) (Brehaut et al.,
479 2004; Guyard et al., 2017; Parkes et al., 2011; Pousada et al., 2013), more qualitative research
480 is needed to obtain an in-depth insight in these parents’ positive and negative experiences. In
481 order to advance this insight, this qualitative study relied on the SDT (Deci & Ryan, 2000),
482 and more specifically on the three basic psychological needs, as a framework to structure
483 these parents’ experiences. Through the exploration of parents’ need-related experiences, we
484 were not only able to identify risks for need-frustration but also to capture opportunities for
485 need-satisfaction. In addition to the three need-related themes, we also retained two themes
486 (i.e., ‘accepting the diagnosis’ and ‘the uncertainty about the future’) that were not directly
487 related to the three psychological needs, but that were important to capture parents’
488 experiences of raising an adolescent with CP. As the five themes identify important targets
489 for parent-support, practical implications will be considered throughout the discussion.

490 ***Parents’ need-related experiences in the context of raising an adolescent with CP***

491 By integrating both negative and positive experiences within the framework of the three
492 basic psychological needs, this study offers a nuanced insight in parents’ wide variety of
493 experiences related to the parenting of their adolescent with CP. In general, parents’

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3 495 parents' freedom, professional careers, relationships with their partner, family, friends, and
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5 496 their own feelings of self-efficacy. Clearly, the impact of raising a child with CP goes beyond
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7 497 parents' parenting role but also transforms their identity more generally.

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10 498 A first important theme concerns challenges for *parents' need for autonomy*. The
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12 499 findings that parents have little time for their own personal interests and feel like they need to
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14 500 give up a lot in order to support their son or daughter with CP, are in line with findings from
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16 501 previous studies. Majnemer and colleagues (2012), for example, reported that about half of
17
18 502 the parents of children and adolescents with CP (aged between 6 and 12 years) experience
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20 503 high levels of stress which negatively impacts their time and emotional state. Parents'
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22 504 difficulties to combine the care for their child with a professional career also corroborate
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24 505 findings from previous qualitative studies (Brehaut et al., 2004). These limitations to pursue a
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26 506 professional career were only reported by mothers and not by fathers, which is in line with
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28 507 research reporting that – on average - mothers spend more time in caregiving tasks than
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30 508 fathers (Byrne, Hurley, Daly, & Cunningham, 2010). Although some mothers expressed
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32 509 regrets about giving up their career or altering their professional ambitions, other mothers
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34 510 stressed the positive effects of this decision (such as having more time to spend with their
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36 511 son/daughter, increased happiness for both the adolescent with CP and the other family
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38 512 members). Based on parents' experiences, we can attribute the limitations in parents'
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40 513 personal freedom and their professional career to the intense and time-consuming care tasks
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42 514 (e.g., bringing the child to therapy), practical difficulties, and the fact that (almost) nobody
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44 515 else can take over the care tasks. This might also explain why these autonomy-frustrating
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46 516 experiences continue to be present, even when children reach adolescence. In mainstream
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48 517 populations, adolescents usually become more self-reliant and autonomous, increasing
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50 518 parents' opportunities to invest more in own interests, friends and work (Galambos &
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519 Castigan, 2003). Because children with CP often need lifelong support and have less
520 opportunities to participate in typical adolescent activities, this “revival of freedom” does not
521 seem to be present among parents of adolescents with CP (Burkhard, 2013; Michelsen et al.,
522 2014). Because frustration of their own need for autonomy has been linked with negative
523 affect, depressive symptoms, and feelings of exhaustion (Bartholomew, Ntoumanis, Ryan,
524 Bosch, & Thogersen-Ntoumani, 2011), it is crucial that these parents receive support to deal
525 with these challenges. For instance, by organizing CP-specific respite care or after-school
526 care, parents would be able to invest more in their personal interests/hobbies or have chances
527 to pursue professional opportunities. It is remarkable that, in this study, we found a total
528 absence of parent-reported need-satisfying experiences concerning their need for autonomy
529 (whereas they did report need-satisfaction concerning relatedness and competence). Future
530 research should further explore possibilities to strengthen autonomy-satisfying experiences
531 among these parents.

532 A second important theme concerned both challenges and opportunities for *parents’*
533 *need for relatedness*. Based on the current results, we can describe the relationship between
534 parents and their adolescent with CP as close and intense, but also as strenuous and
535 exhausting. Due to the care tasks and the required adaptations, parents are highly involved in
536 the life of their adolescent with CP. That is, adolescents with CP depend strongly on the
537 emotional and practical support of their parents which fosters the relatedness between them.
538 Parents often have a good understanding of their son’s or daughter’s feelings, thoughts,
539 desires and intentions. These positive findings are in line with the study of Björquist,
540 Nordmark, and Hallström (2015) showing that parents appreciate having a close relationship
541 with their adolescent with CP and realize that other parents often spend less time with their
542 adolescent. Although this close relationship can result in satisfaction of parents’ need for
543 relatedness with their son or daughter, it can also put additional pressure on parents. That is,

544 parents can feel so indispensable for their adolescent's well-being that they experience a loss
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2 545 of their own individuality and feel like they are fused together with their son or daughter,
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4 546 which can lead to feelings of exhaustion and overprotective behavior (Hamilton et al., 2015;
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7 547 Jankowska, Wlodarczyj, Campbell, & Shaw, 2015; Ho et al., 2008; Pelchat, Levert, &
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10 548 Bourgeois-Guerin, 2009). Parents' relatedness-related experiences did not only concern their
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12 549 relationship with the adolescent with CP but also with their other children, their partner,
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14 550 friends and family. The finding that the intense care for a child with CP poses threats for
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17 551 parents' relationships with their other children corroborates research among other chronic
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19 552 conditions (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2007; Waite-Jones & Madill,
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22 553 2008). Because parents find it important that their other children can pursue their own
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24 554 interests and receive personal attention, they organize special activities or split up the family
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27 555 for doing certain activities with the siblings. These findings corroborate studies on siblings of
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29 556 children with a disability showing that siblings express a need for private time with their
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32 557 parents (Moysen & Roeyers, 2012). Moreover, parents' need-satisfying experiences
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34 558 concerning their relationship with their partner are in line with other studies indicating that –
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37 559 in some families - raising a child with CP strengthens parents' relationship because parents
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39 560 work together as a team to provide the best care for their child with CP (Björquist et al.,
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41 561 2015). The current study also showed that the partner often is the only one who really
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44 562 understands the difficulties and challenges that the family experiences, causing parents to
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46 563 turn more to each other for emotional support. However, raising a child with CP can, at least
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49 564 for some parents, also have a negative impact on the relatedness between parents. Parents
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51 565 indicate that the intense healthcare and the necessity to split up the family to do activities
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54 566 limit the time spent together, which can hamper parents' relationship. In order to interpret the
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56 567 current findings concerning the relatedness between parents, we need to take into account that
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59 568 some interviews were conducted with couples and other interviews with mothers alone. The
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569 interviewed couples did not mention any need-frustrating experiences affecting their partner
570 relationship, whereas some mothers who were interviewed alone did mention need-frustrating
571 experiences, such as the effects of splitting up the family. It is possible that parents who
572 participated as a couple were less willing to discuss challenges for their relatedness with the
573 interviewer, whereas mothers who participated alone might have felt more freedom to discuss
574 challenges concerning the relationship with their partner. Another explanation for this finding
575 is that parents whose relationships are not deeply affected by raising a child with CP might
576 have been more willing to participate as a couple than parents who were experiencing more
577 challenges in their relationship. As positive family relationships are a crucial protective factor
578 for the well-being in families of children with CP (Guyard et al., 2017), it is important for
579 support providers to pay adequate attention to the relationships among all family members.

580 Raising a child with CP does not only affect the relatedness within the family, but also
581 the relatedness with other relatives and friends. The need-satisfying experiences indicate that
582 perceiving support or understanding from the broader network is essential for parents'
583 feelings of relatedness with relatives, friends, and other parents of children with CP. The
584 relationships that develop, continue to exist or even strengthen in times when parents are
585 experiencing challenges related to their child with CP (e.g., after receiving the diagnosis,
586 when choosing a suitable school), actually become more meaningful and valuable for parents
587 and clearly satisfy parents' need for relatedness. The many reported need-frustrating
588 experiences, however, indicate that raising a child with CP can also put pressure on
589 relationships with the broader network. Parents attribute this to practical difficulties and a
590 lack of energy which affect the amount of time that they can spend with friends. Parents'
591 relationships with relatives and friends are hampered when parents feel misunderstood by
592 their environment or even feel socially excluded. These need-frustrating experiences mesh
593 with studies reporting unsupportive interactions and social isolation and seclusion among

1 594 parents of children with CP (Alaee et al., 2015; Florian & Findler, 2001). This finding in
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3 595 combination with the finding that having a supportive network and social support are
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5 596 important determinants of parents' well-being (Pousada et al., 2013), highlight the
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7 597 importance and the potential of targeting relatedness during counselling. In order to increase
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9 598 comprehension from the broader network, health care providers could, for instance, help
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11 599 parents to inform relatives and friends about their experiences. Another way to support
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13 600 parents' need for relatedness might be by bringing parents in contact with other parents of
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15 601 children with CP. Finally, parents also discussed the relationships they built towards
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17 602 healthcare providers. Parents reported that the relatedness with health care providers is
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19 603 strongly affected by the attitude of healthcare providers. By being genuinely motivated to
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21 604 improve the child's and family's well-being and by taking a positive and solution-oriented
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23 605 approach to do this, healthcare providers strengthen their relationship with parents. These
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25 606 findings corroborate the determinants for parents' satisfaction with health care that were
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27 607 recently described by Molinaro and colleagues (2017) in their study about family-centered
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29 608 care for families with CP: parents need (1) a respectful and supportive attitude of health care
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31 609 providers, (2) a balanced partnership in care (i.e., parents are recognized as experts and are
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33 610 actively involved in decision making), and (3) access to correct and comprehensible
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35 611 information.

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37 612 In sum, relatedness appears to be a very salient theme within parent's experiences while
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39 613 raising a child with CP. Although we found that some relationships might actually be
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41 614 strengthened by raising a child with CP, parents' need for relatedness remains vulnerable.
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43 615 Furthermore, healthcare providers should not only be aware of the relatedness between them
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45 616 and the parents, but should also pay attention to the quality of parents' relationships within
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47 617 (i.e., with partner, siblings) and outside the family (i.e., friends, relatives).
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618 A third important theme concerns parents' *feelings of competence*. Within this theme,
619 we identified a subtheme that concerned need-satisfying experiences, 'achieving the
620 unexpected', and two subthemes that concerned need-frustrating experiences, 'feeling
621 exhausted' and 'feeling powerless'. Parents' feelings of competence and self-efficacy are
622 clearly strengthened when they notice that their efforts are improving their child's
623 functioning or well-being. When parents have had these competence-satisfying experiences
624 in the past, it helps them to persevere during more difficult periods and gives them hope that,
625 with time and patience, their efforts will help to reach their goal. This finding corroborates
626 research identifying self-efficacy and feelings of competence as important determinants of
627 parents' mental health and functioning among parents of children and adolescents with CP
628 (Jankowska et al., 2015; Pousada et al., 2013). This suggests that identifying and
629 acknowledging signals of improvements might strengthen parents' feelings of competence
630 and might help them to persevere or to keep up all their efforts.

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631 The current results also show, however, that providing the intense emotional and
632 physical care can really drain parents' energy or can even make them feel like they are not
633 able to offer the required support. Based on these results, it seems that it is the combination of
634 offering practical and emotional support and the very intense character of this support that
635 can cause feelings of physical and/or emotional exhaustion in parents. This finding meshes
636 with the study of Guyard et al. (2017) which shows that respite care is an important
637 environmental factor that is related with lower levels of parental distress. Investing in respite
638 care or in organized at-home support for families with children and adolescents with CP
639 might be a way to support parents' feelings of competence and to avoid that they feel
640 overcharged (Guyard et al., 2017). Feelings of powerlessness were mainly reported in
641 reference to medical procedures and the rehabilitation process afterwards. The finding that
642 the period of a surgery and the recovery is very hard for parents is in line with findings of

1 643 Whittingham, Wee, Sanders, and Boyd (2013) and stress the importance of qualitative
2 644 support during this period. Parents indicated that they would be better able to deal with the
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4 645 process of the surgery and the recovery if they would receive more and specific information
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7 646 and if they would have access to practical (at-home) support. In sum, parents' need for
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10 647 competence might be challenged by the emotional and practical care that they need to
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12 648 provide, especially when the child needs a medical procedure or surgery. Nevertheless,
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14 649 noticing that their efforts help their son or daughter to achieve the unexpected, fosters
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17 650 parents' feelings of efficacy and gives them energy to persevere.

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19 651 Taken together, the framework of the three basic psychological needs allowed for an in-
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21 652 depth understanding of parents' positive and negative experiences. The most salient theme
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24 653 was the theme concerning parents' need for relatedness. Raising a child with CP clearly
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26 654 creates diverse opportunities for close relationships but also entails multiple threats for
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29 655 loneliness or social exclusion. Concerning parents' need for autonomy, we could not identify
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31 656 need-satisfying experiences. The finding that parents' feelings of volitional functioning are
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34 657 put under a lot of pressure due to practical issues definitely needs to be taken into account
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36 658 during counselling or when promoting psychosocial outcomes in this population. Finally,
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39 659 parents' need for competence can be threatened when the emotional and practical care
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41 660 exhausts them or when they feel like they are not able to help their child. Beating the odds
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44 661 and achieving unexpected goals, on the other hand, can boost parents' feelings of
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46 662 competence.

47 48 49 663 *The importance of accepting the diagnosis*

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51 664 In addition to the three need-related themes, we also identified the acceptance of the
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53 665 diagnosis as an essential part of parents' experiences of raising a child with CP. Parents
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56 666 indicated, in line with previous research, that coming to terms with the fact that their child is
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58 667 affected by a permanent disorder is a difficult yet important process (Marvin & Pianta, 1996;
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668 Pelchat et al., 2009). Parents' acceptance of the diagnosis is often examined during a child's
669 infancy because this is the time when the acceptance process starts (e.g., Rentinck, Ketelaar,
670 Jongmans, Lindeman, & Gorter). The current findings, however, indicate that this is a long-
671 term process that strongly impacts on parents' personal well-being. As indicated by Hastings
672 and colleagues (2015), adolescence might be a developmental phase in which parents are
673 confronted with new feelings of grief because parents need (once more) to let go of certain
674 expectations about their son/daughter (e.g., living independently is not evident) and
675 themselves (e.g., care tasks are not diminishing).

676 Although this process of accepting the diagnosis could not be structured within the
677 framework of the three basic psychological needs, it does relate with another concept that is
678 central to SDT, that is, the process of internalization. Through the process of internalization,
679 parents experience their identity as a parent of a child with CP as meaningful and a reflection
680 of who they are (i.e., identification) or integrate this identity with other values and goals (i.e.,
681 integration) (Ryan & Deci, 2003; Soenens & Vansteenkiste, 2011). This process allows
682 people to identify more strongly with their commitments and wholeheartedly endorse them.
683 By accepting the child's diagnosis, parents might simultaneously accept their identity as a
684 parent of a child with CP more and align this identity within their self and their other values
685 and goals. Because internalization lays the foundation for need-satisfying experiences,
686 parents who are able to come to terms with the diagnosis might also experience more need-
687 satisfaction (Ryan & Deci, 2017). Findings indicating that parents who have more difficulties
688 to accept the diagnosis (i.e., unresolved parents) focus more on the negative aspects of their
689 child's disability and consequently experience more stress (Marvin & Pianta, 1996; Sheeran,
690 Marvin, & Pianta, 1997), suggest that these parents might be more at risk to experience
691 challenges encountered during the parenting process as need-frustrating.

692 In line with studies reporting that parents of children with CP can experience feelings
693 of guilt (irrespective of the real cause of the disability) (Findler, Jacoby, & Gabis, 2016;
694 Francis, 2012; Huang et al., 2010), we also found that some mothers expressed feeling guilty.
695 Although guilt is not directly related with parents' psychological needs, it is possible that
696 feelings of guilt affect parents' need-related experiences. For instance, a parent who feels
697 guilty about their child's disability might focus excessively on taking care of his/her child
698 and, as a consequence, might choose to invest less in personal hobbies or social relationships,
699 hence exacerbating frustration of his/her need for autonomy and relatedness (Pelchat et al.,
700 2009). Parents might also think that they will never be able to make up for their child's
701 difficulties and, thus, feel like a failure as a parent (i.e., competence frustration). In order to
702 examine the association between parents' acceptance of the diagnosis and their need-related
703 experiences more in-depth, future research could conduct questionnaire (including, for
704 instance, the Reaction to Diagnosis Interview (Marvin & Pianta 1996)) or mixed-method
705 studies probing deeper cognitions or attributions of parents. Given that feelings of guilt might
706 contribute to less happiness and more pressure among parents (Findler et al., 2016; Ryan &
707 Deci, 2017), which in turn can affect how parents interact with their child (Ryan & Deci,
708 2017), it is important that healthcare providers are aware of and pay attention to feelings of
709 guilt among parents of adolescents with CP.

What is lying ahead? The impact of the uncertainty about the future

711 The finding that all participating parents felt worried about the future of their son or
712 daughter is in line with other qualitative studies examining parents' personal experiences in
713 the context of CP (Alaee et al., 2015; Björquist et al., 2015; Whittingham et al., 2013). One of
714 the most important worries related to what would happen when the parents themselves or no
715 longer able to support or help their son/daughter or when they pass away. In line with
716 previous findings (Alaee et al., 2015), parents do not assume or do not wish that siblings or

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717 other family members take over the care of their child. In the current study, parents also
718 expressed a lot of worries and uncertainty about the services and financial aid that will be
719 available once their child finishes secondary school. This is in line with the finding of
720 Palisano and colleagues (2009) that 50% of the parents of a child with a disability ask for
721 more information about current or future available services. Parents try to deal with these
722 worries by seeking for information, but often a lot of their questions remain unanswered. In
723 order to help parents in this search for answers, healthcare providers should inquire parents
724 (and other family members) not only about acute problems or worries but also about more
725 long-term worries or hypothetical problems. As parents' worries might change throughout the
726 development of the child, it is important to organize a support- or healthcare system that
727 offers guidance or counselling throughout each developmental phase of the child's life.

Limitations and directions for future research

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

740 A second limitation concerns the limited sample that was conducted within a specific
741 region (i.e., Flanders, Belgium). Because parents' experiences possibly depended upon

1 742 regional available support, their experiences might differ from parents living in other regions.

2 743 Nevertheless, the results do show clear similarities with studies from other countries, which

3 744 indicates that many experiences are shared across regions, at least in Western countries.

4 745 Other demographic characteristics of the participating parents and their children might

5 746 also impact the generalizability of this study. Current results might, for instance, be affected

6 747 by the fact that most children of the current sample had higher levels of functional ability

7 748 (i.e., eight children had a GMFCS level I or II and one child with level V). Future research

8 749 should examine more in-depth whether parents' need-related experiences, their acceptance of

9 750 the diagnosis and their worries relate with disability severity by recruiting a more

10 751 heterogeneous sample or by focusing on specific subsamples. Another demographic

11 752 characteristic that might limit the generalizability of the findings is the focus on parents of

12 753 adolescents. When interpreting, for instance, the results concerning competence, we need to

13 754 take into account that the participating parents already have a lot of experience in dealing

14 755 with the practical and emotional challenges of raising a child with CP. This might explain

15 756 why parents reported fewer competence-related experiences in comparison to autonomy- and

16 757 relatedness experiences. It might be interesting to examine whether parents' competence-

17 758 related experiences change throughout the development of the child.

18 759 Finally, these qualitative findings do not allow to draw conclusions about relations

19 760 between the identified themes. Therefore, prospective longitudinal studies are needed,

20 761 combining more quantitative methods (e.g., observations, standardized questionnaires) as

21 762 well as more in-depth qualitative methods (e.g., into more underlying motives and feelings).

22 763 It would be, for instance, interesting to examine the association between parents' reaction to

23 764 the diagnosis, their internalization of their identity as a parent of a child with CP, and their

24 765 need-related experiences.

25 766 **Conclusion**

1 767 By relying on the three basic psychological needs, as described by the SDT, this
2 768 qualitative study offered an in-depth insight into the complex experiences of parents of
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4 769 adolescents with CP. Although raising an adolescent with CP entails threats for parents’
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7 770 freedom, professional career, personal relationships, and their feelings of self-efficacy, it can
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10 771 –at the same time- also offer opportunities to feel closely connected with others (including
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12 772 the experience of a valued, special relationship with the child with CP) and to feel effective
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14 773 when the unexpected can be achieved together. In addition to these need-frustrating and need-
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17 774 supportive experiences, parents’ acceptance of the diagnosis and parents’ worries about their
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19 775 child’s future are also essential themes to take into account as keys to provide better parent
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22 776 support.

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24 777 **No conflict of interest**

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26 778 On behalf of all authors, the corresponding author states that there is no conflict of
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Table 1. *Demographic characteristics of participants*

Parent information & 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	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

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

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

“I am partially her shadow”

Lisa M. Dieleman^a

Roos Van Vlaenderen

Ghent University, Belgium

Peter Prinzie^b

Erasmus University Rotterdam, the Netherlands

Sarah S.W. De Pauw^c

Ghent University, Belgium

Author Information:

^aGhent University, Department of Developmental, Personality and Social Psychology
Henri Dunantlaan 2, 9000 Gent, Belgium
Tel: +32 09 264 64 15
Lisa.Dieleman@UGent.be

^bErasmus University Rotterdam, Faculty of Social Sciences, Department of Psychology,
Education & Child Studies
Burg. Oudlaan 50, 3000 DR Rotterdam, The Netherlands
Tel: +31 010 4082598
Prinzie@essb.eur.nl

^cGhent University, Department of Special Needs Education
Henri Dunantlaan 2, 9000 Ghent, Belgium
Tel: +32 09 331 03 12
Sarah.Depauw@UGent.be

Corresponding author:

E-mail: Lisa.Dieleman@UGent.be
Phone: ++32 9 264 64 15

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