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2 **Parenting an infant with a congenital anomaly: How are perceived burden and**  
3 **perceived personal benefits related to parenting stress?**

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5  
6 **Abstract**

7 This study aimed to characterize parents' negative (perceived burden) and positive  
8 (perceived personal benefits) perceptions about parenting an infant with a congenital  
9 anomaly (CA), and to investigate their role in parenting stress. Forty-three couples (43  
10 mothers and 36 fathers) whose six-month-old infants had a CA completed several  
11 questionnaires: the Impact on Family Scale-Revised, the Positive Contributions Scale,  
12 and the Parenting Stress Index-Short Form. The results showed similarities between  
13 maternal and paternal perceptions. For mothers, higher levels of burden and lower levels  
14 of personal benefits were found to predict higher levels of parenting stress. For fathers,  
15 greater burden was associated with higher levels of parenting stress. Some dimensions  
16 of personal benefits moderated the relationship between burden and parenting stress, for  
17 both genders. Specific strategies targeting negative and positive perceptions should be  
18 considered when developing psychological interventions to promote the family's  
19 adaptation to the experience of parenting an infant with a CA.

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21 **Key-words:** parenting stress; parents of infants with a congenital anomaly; perceived  
22 burden; perceived personal benefits.

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27           Parenting an infant with a congenital anomaly (CA), a structural or functional  
28 anomaly present at birth that arises during intrauterine development, may be particularly  
29 demanding (Crowley, 2010). CAs include: anomalies of the nervous system, eye, ear,  
30 face and neck; congenital heart diseases; anomalies of the respiratory, digestive, urinary,  
31 and musculoskeletal systems; and anomalies of the genital organs and other types of CA  
32 (World Health Organization [WHO], 1992). In addition to the usual caretaking tasks,  
33 parents must address the disrupted expectations of having a healthy baby (Aite et al.,  
34 2003) and the challenges of care, e.g.: increased medical demands, such as surgeries,  
35 hospitalizations, and medical monitoring; uncertainty about the future; and parent-child  
36 interaction difficulties; (Laing et al., 2010; Mazer et al., 2008; Messias, Gilliss,  
37 Sparacino, Tong, & Foote, 1995; Montirosso et al., 2012). Therefore, the first months  
38 after the birth of an infant with a CA are particularly challenging and require individual  
39 and familial reorganizations to cope with the caregiving demands (Messias et al., 1995).

40           Family stress theories (Boss, 2002) emphasize the important role of family  
41 members' perceptions about the stressor event (i.e., parenting an infant with a CA) in  
42 explaining the family's adaptation response. When considering the parenting  
43 experience, family adaptation may be assessed by the parents' levels of parenting stress.  
44 Parenting stress is defined as the "aversive psychological reaction to the demands of  
45 being a parent" (p. 315), which is experienced by parents as negative feelings towards  
46 the self and the child (Deater-Deckard, 1998). According to Abidin (1992), parenting  
47 stress results from perceiving a disparity between the demands of the parental role and  
48 the resources available to meet those requirements, emphasizing the role of individual  
49 perceptions about the parental role in explaining the stress levels. Although all parents  
50 experience parenting stress to some degree (Deater-Deckard, 1998), levels of stress tend

51 to be higher in parents of infants with a CA than in parents of healthy infants (Smith,  
52 Oliver, & Innocenti, 2001; Uzark & Jones, 2003). As parenting stress shows a pattern of  
53 a relatively stable and gradual increase over time among parents of children with  
54 CA/disabilities (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001) and may have  
55 detrimental consequences in parenting practices (Crnic & Low, 2002), it is critical to  
56 develop effective early interventions aiming to reduce parenting stress among this  
57 group. As parental perceptions may be a modifiable target of these early psychological  
58 interventions, it is important to understand their role on parents' levels of parenting  
59 stress.

60 Research shows that parents of children with CA/disabilities have negative  
61 perceptions concerning their caregiving experience. Specifically, they perceive their  
62 caregiving experience to have individual (e.g., constant worry, physical exhaustion, lack  
63 of freedom), familial/social (e.g., less contact with family and friends, difficulty making  
64 plans), and professional/financial (e.g., financial difficulties) consequences, which are  
65 seen as burdensome and overwhelming (Baker, Owens, Stern, & Willmot, 2009;  
66 Coffey, 2006; Green, 2007; Hunfeld, Tempels, Passchier, Hazebroek, & Tibboel, 1999;  
67 Kramer, Baethge, Sinikovic, & Schliephake, 2007).

68 Although research has focused mainly on negative perceptions about the  
69 demands of caring for a child with a CA, some studies found that parents may also  
70 perceive personal benefits (positive perceptions) associated with their parenting  
71 experience, including personal growth, family cohesion, strengthening of the social  
72 network, and the development of their spiritual belief system (Bayat, 2007; Behr,  
73 Murphy, & Summers, 1992; Hastings, Allen, McDermott, & Still, 2002; Hastings,  
74 Beck, & Hill, 2005; Heiman, 2002; Scorgie & Sobsey, 2000). Moreover, positive and  
75 negative perceptions about the parenting experience seem to occur independently, i.e.,

76 parents may simultaneously perceive caregiving demands/burden and personal benefits  
77 associated with the experience of parenting a child with a CA (Hastings, Beck, et al.,  
78 2005; Mak & Ho, 2007). As most of the studies comprise parents of preschool- and  
79 school-aged children, negative and positive perceptions about the experience of  
80 parenting an infant with a CA during the first months post-birth should be further  
81 examined.

82         Gender specificities concerning perceptions about the parenting experience  
83 should also be taken into account, since mothers and fathers tend to adopt different roles  
84 after an infant's birth. Whereas mothers assume the role of main caregivers, fathers  
85 assume the role of providers (Katz-Wise, Priess, & Hyde, 2010), which may lead to  
86 different perceptions about the demands, but also about the benefits of caring for an  
87 infant with a CA. Although the existing knowledge about this topic is limited by the fact  
88 that the majority of studies comprise only mothers, it has been found that mothers  
89 perceive higher levels of burden (Hunfeld et al., 1999) as well as more personal benefits  
90 than fathers (Albuquerque, Pereira, Fonseca, & Canavarro, 2013; Hastings, Kovshoff, et  
91 al., 2005). However, other studies have found no gender differences in the perceived  
92 burden of caring for an infant with a CA (Albuquerque, 2011), suggesting that there  
93 may be some similarities between maternal and paternal perceptions. In fact, a number  
94 of recent studies have shown that after the diagnosis of CA, the paternal figure tends to  
95 assume a protective and supportive role for his partner (Locock & Alexander, 2006),  
96 leading to greater paternal involvement in caregiving tasks (Huang, Chen, & Tsai, 2012;  
97 Simmerman, Balcher, & Baker, 2001), which may explain the similarity of maternal  
98 and paternal experiences.

99         In accordance with family stress theories (Boss, 2002), it is expected that more  
100 negative perceptions about the experience of parenting an infant with a CA will

101 contribute to higher levels of parenting stress. However, this topic has been scarcely  
102 investigated and we only know of one study (Fonseca, Nazaré, & Canavarro, in press)  
103 which found a positive association between maternal and paternal levels of perceived  
104 burden and parenting stress.

105         The role of positive perceptions about the parenting experience in family's  
106 adaptation to the infant's CA should also be considered. The perception of personal  
107 benefits results from the parents' search for meaning concerning the experience of  
108 caring for an infant with a CA (King et al., 2006; Larson, 2010), and seems to be one of  
109 the determinants of successful parental adaptation to their child's CA (Behr et al.,  
110 1992). In fact, one recent study found that, after the prenatal diagnosis of a CA, the  
111 mothers who tried to see the situation as an opportunity for personal development  
112 presented better adjustment (Rychik et al., 2013). Some authors suggest that the  
113 perception of personal benefits is associated with an optimistic view of the future that  
114 allows the mobilization of the resources needed to address the perceived demands of  
115 caring for a child with a CA (Kearney & Griffin, 2001; King et al., 2006). For example,  
116 Rychick et al. (2013) found that mothers who tried to see their infant's prenatal  
117 diagnosis of CA as an opportunity for personal development reported an increased use  
118 of emotional and instrumental social support to deal with the situation. Thus, it is  
119 reasonable to hypothesize that the effect of perceived burden in parenting stress may  
120 vary according to the perceived personal benefits of the experience of parenting an  
121 infant with a CA.

122         Based on the previously mentioned literature gaps, this study focused on the  
123 experience of parents of infants with a CA, six months post-birth, with two main goals.  
124 The first goal was to characterize negative (perceived burden) and positive (perceived  
125 personal benefits) perceptions of the caregiving experience, by: a) examining gender

126 differences in both negative and positive perceptions; and b) examining the association  
127 between positive and negative perceptions, for both mothers and fathers. The second  
128 goal was to examine the effects of perceptions about the parenting experience in  
129 maternal and paternal parenting stress levels, by: a) examining the main effects of  
130 negative and positive perceptions in parenting stress; and b) examining the moderator  
131 effect of positive perceptions in the relationship between negative perceptions and  
132 parenting stress.

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## Methods

### 135 Participants and Procedure

136 This study is part of a longitudinal study titled “Reproductive decisions and  
137 transition to parenthood after a pre- or postnatal diagnosis of a CA”, which was  
138 approved by the Ethics Committees of the Hospitais da Universidade de Coimbra  
139 (HUC) and the Centro Hospitalar de Coimbra (CHC), Portugal. Inclusion criteria for  
140 this study were: 1) having an infant who was pre- or postnatally diagnosed with a CA,  
141 without the occurrence of perinatal death; 2) being at least 18 years of age; and 3)  
142 having a level of literacy (educational level  $\geq$  sixth grade) that allowed for  
143 comprehension of the assessment protocol. The data collection took place between  
144 September 2009 and February 2012 in the Obstetrics and Neonatology Departments of  
145 HUC and in the Pediatric Cardiology Service of the Pediatric Hospital (CHC).  
146 Approximately one month after the disclosure of a diagnosis of a CA, all parents were  
147 informed of this study by their medical team at the end of a medical appointment and  
148 contacted by the researchers. Those who decided to participate signed an informed  
149 consent form and completed the assessment protocol (Time 1). Eighty-two couples were  
150 contacted, of whom 22 refused to participate and/or did not return the questionnaires

151 (participation rate: 73.17%). Parents were again contacted six months after the infant's  
152 birth (Time 2). The questionnaires were mailed to the participants along with a pre-  
153 stamped envelope to return the questionnaires after completion; 17 couples did not  
154 return the questionnaires at Time 2 (attrition rate: 28.33%) and in seven cases,  
155 questionnaires were completed only by women. No significant differences in  
156 sociodemographic or clinical characteristics were found in parents who returned or did  
157 not return the questionnaires at Time 2. For the purpose of this study, only parents who  
158 participated at Time 2 were considered (cross-sectional data). The sample included  
159 parents of 43 infants with a CA (43 mothers and 36 fathers). The sample characteristics  
160 are presented in Table 1 and the infant's clinical information is presented in Table 2.

161 [Insert\_Table\_1\_about\_here]

162 [Insert\_Table\_2\_about\_here]

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## 164 **Measures**

165 **Sociodemographic and clinical data.** A questionnaire was used to obtain  
166 sociodemographic information (gender, age, educational level, marital status, and  
167 professional status), clinical information for mothers (parity; history of pregnancy loss)  
168 and clinical information for infants (type of CA, timing of diagnosis, need for surgery  
169 and hospitalization).

170 **Negative perceptions.** Negative perceptions (perceived burden) about caring for  
171 an infant with a CA were assessed using the Portuguese version of the Impact on Family  
172 Scale – Revised (IOF-R; Stein & Jessop, 2003 [original version of IOF-R];  
173 Albuquerque, Fonseca, Pereira, Nazaré, & Canavarro, 2011 [Portuguese version of IOF-  
174 R]). This unidimensional scale was developed to assess parental perceptions about the  
175 effects of a child's medical condition in family life (Stein & Jessop, 2003). The scale

176 consists of 15 items (e.g., “Fatigue is a problem for me because of my child’s illness;”  
177 “Sometimes we have to change plans about going out at the last minute because of my  
178 child’s state”), answered on a four-point scale (from 1 = *Strongly disagree* to 4 =  
179 *Strongly agree*). Higher scores indicate a greater perceived burden associated with  
180 caring for an infant with a CA (i.e., more negative perceptions). Cronbach’s alpha in our  
181 sample was .92 for mothers and .94 for fathers.

182       **Positive perceptions.** To assess the perceived personal benefits associated with  
183 the experience of caring for an infant with a CA, we used the Portuguese version of the  
184 Positive Contributions Scale of the Kansas Inventory of Parental Perceptions (PCS;  
185 Behr et al., 1992 [original version of PCS]; Fonseca, Nazaré, Albuquerque, Pereira, &  
186 Canavarro, 2013 [Portuguese version of PCS]). This scale consists of 43 items, each  
187 answered on a four-point scale (from 1 = *Strongly disagree* to 4 = *Strongly agree*), and  
188 is organized along six dimensions: 1) Personal Growth and Awareness of the Future,  
189 with 12 items that focus on the child as a source of parents’ development of important  
190 personal characteristics/skills, such as patience and time management, e.g., “My child is  
191 why I am a more responsible person” and “My child is what makes me realize the  
192 importance of planning for my family’s future;” 2) Learning Through Experience with  
193 Special Problems in Life, with 9 items that focus on the child as a source of parents  
194 having higher sensitivity and attention to the needs and rights of people with special  
195 needs, e.g., “The presence of my child helps me understand people who are different”  
196 and “My child is responsible for my increased awareness of people with special needs;”  
197 3) Acceptance and Family Cohesion, with 8 items that focus on the child as a source of  
198 increased parental acceptance of the challenges of everyday life and family cohesion  
199 and unity, e.g., “Because of my child, I am more accepting of things” and “Because of  
200 my child, our family has become closer;” 4) Happiness and Affection, with 5 items that

201 focus on the child as a source of rewarding moments and affection for parents, e.g.,  
202 “The presence of my child cheers me up” and “My child is very affectionate;” 5)  
203 Spirituality, with 5 items that focus on the child as a source of parent  
204 development/reinforcement of spiritual beliefs, e.g., “The presence of my child is a  
205 reminder that everyone has a purpose in life” and “The presence of my child confirms  
206 my faith in God;” and 6) Expanded Social Network, with 4 items that focus on the child  
207 as a source of new interpersonal relationships for parents, e.g., “Because of my child,  
208 my social life has expanded by bringing me into contact with other parents” and “My  
209 child is why I met some of my best friends.” Higher scores indicate a greater perception  
210 of personal benefits associated with caring for an infant with a CA (i.e., more positive  
211 perceptions). Cronbach’s alpha in our sample ranged from .73 (fathers – Expanded  
212 Social Network) to .93 (mothers – Happiness and Affection). Spirituality was excluded  
213 from this study because Cronbach’s alphas were .64 (mothers) and .53 (fathers).

214 **Parenting stress.** The stress within the parent-child system was assessed with  
215 the Portuguese version of the Parenting Stress Index – Short Form (PSI-SF; Abidin,  
216 1995 [original version of PSI-SF]; Santos, 2011 [Portuguese version of PSI-SF]). The  
217 scale comprises 36 items, answered on a five-point scale (from 1 = *Completely disagree*  
218 to 5 = *Completely agree*), and is organized along three dimensions: 1) Parental Distress,  
219 with 12 items that focus on distress that directly relates to parenting, e.g., “I don’t enjoy  
220 things as I used to” and “I often have the feeling that I cannot handle things very well;”  
221 2) Parent-Child Dysfunctional Interaction, with 12 items that focus on the parents’  
222 dissatisfaction with interactions and with how the child meets the parents’ expectations,  
223 e.g., “My child rarely does things for me that make me feel good” and “Sometimes I  
224 feel my child does not like me and does not want to be close to me;” and 3) Difficult  
225 Child, with 12 items that focus on parents’ dissatisfaction with basic characteristics of

226 the child, e.g., “My child does a few things that bother me a great deal” and “My child  
227 seems to cry or fuss more often than most children.” It is also possible to compute a  
228 total score of parenting stress, which was used in this study. Higher scores indicate  
229 greater stress within the parent-child system. Cronbach’s alphas in our sample were .93  
230 for fathers and .95 for mothers.

231 The translation procedure and validation process used to generate Portuguese  
232 versions of the three measures above has been described in the previously cited papers  
233 (e.g., Albuquerque et al., 2011; Fonseca et al., 2013). The procedures involved:  
234 individual translation by two Psychologists fluent in English; back translation; and  
235 discussion of the items with health professionals working in the field, with potential  
236 respondents, and with the authors of the original versions of the instruments.

### 237 **Data analyses**

238 Analyses were conducted using IBM SPSS, version 19.0. Descriptive statistics  
239 and comparison tests were used for the sociodemographic characterization of the sample  
240 (independent sample *t*-tests and chi-squared tests). Regarding our first goal, gender  
241 differences in parental perceptions were examined with paired *t*-tests (perceived burden)  
242 and repeated-measures MANOVA (perceived personal benefits), followed by ANOVAs  
243 when the multivariate effect was significant. These analyses were performed on the  
244 couple as a unit (the database was restructured to consider each couple as the subject of  
245 the analysis and each partner’s score as a different variable; gender – mothers vs. fathers  
246 – was considered the within-subjects factor), to account for couple non-independence  
247 (Cook & Kenny, 2005). Therefore, concerning the first goal, the seven couples in which  
248 only the mothers completed the questionnaires were not included in the analyses.  
249 Bivariate Pearson correlations were computed to examine the association between  
250 perceived burden and the dimensions of personal benefits.

251           Regarding our second goal, to examine the effects of negative and positive  
252 perceptions in maternal and paternal levels of parenting stress, multiple linear  
253 regressions were performed. The regression analyses were conducted separately for  
254 mothers ( $n = 43$ ) and fathers ( $n = 36$ ), due to couple non-independence (Cook & Kenny,  
255 2005). For control purposes, sociodemographic (age, educational level) and clinical  
256 variables (parity, timing of diagnosis, type of CA, hospitalization, need of surgery) were  
257 entered in the models, if they were significantly associated with parenting stress. The  
258 Kruskal-Wallis test – for type of CA – and bivariate Pearson correlations – for the  
259 remaining variables – were used to examine the associations between sociodemographic  
260 and clinical variables and the study variables. Moderation effects were analyzed in  
261 accordance with Aiken and West (1991). In each multiple regression, both the predictor  
262 (negative perception) and the moderator (positive perception) were included (after  
263 centering procedures to avoid multicollinearity) in the first step of the regression model  
264 (assessment of main effects). In the second step, the interaction term (negative  
265 perception x positive perception) was introduced. Significant interactions were plotted,  
266 and post-hoc simple slope analyses were conducted using Modgraph (Jose, 2008) to  
267 determine their nature.

268           Effect-size measures are presented for the comparison analyses (small:  $\eta^2 \geq .01$ ,  
269  $d \geq .20$ ; medium:  $\eta^2 \geq .06$ ,  $d \geq .50$ ; large:  $\eta^2 \geq .14$ ,  $d \geq .80$ ). The post-hoc power  
270 calculations conducted for the analyses performed with a significance level of .05 and  
271 power  $\geq .80$  indicated that medium ( $f^2 = .25$ , for comparison analyses;  $f^2 = .28$ , for  
272 multiple regression analyses) to large effects could be detected (Faul, Erdfelder, Lang,  
273 & Buchner, 2007). The statistical significance level was set to  $p < .05$ , but marginally  
274 significant results ( $p < .10$ ) are reported and discussed.

275

## Results

### Characterization of negative and positive perceptions about the experience of parenting an infant with a CA

Table 3 presents the descriptive statistics for the main study variables, i.e., negative perceptions, positive perceptions and parenting stress.

[Insert\_Table\_3\_about\_here]

#### Gender comparisons.

There were no gender differences in negative perceptions ( $t(35) = -0.05, p = .959, d = .01$ ). The multivariate effect of gender in positive perceptions was also not significant (Pillai's Trace = .03,  $F(5, 31) = 0.16, p = .976, \eta^2 = .03$ ).

#### Associations between negative and positive perceptions.

Table 4 presents the bivariate associations between parents' negative and positive perceptions, parenting stress and sociodemographic and clinical variables. Correlations for mothers are presented in the upper portion of the Table, and correlations for fathers in the lower portion of the Table. Type of CA was not associated with parents' perceived burden (mothers:  $Z = -0.24, p = .812$ ; fathers:  $Z = -0.82, p = .411$ ) or parenting stress (mothers:  $Z = -1.13, p = .257$ ; fathers:  $Z = -0.88, p = .377$ ).

[Insert\_Table\_4\_about\_here]

No significant associations were found between negative and positive perceptions, with the sole exception of an association between maternal negative perceptions and one

300 maternal positive perception (i.e., Learning Through Experience), suggesting  
301 independence among the study variables (see Table 4).

302

303 **Effects of perceptions about the parenting experience on maternal and paternal**  
304 **parenting stress levels**

305

306 **Maternal parenting stress.**

307 Table 5 presents the regression models examining the main and interaction  
308 effects of mothers' negative and positive perceptions on maternal parenting stress.

309 [Insert\_Table\_5\_about\_here]

310

311 For mothers, more negative perceptions predicted higher levels of parenting stress.  
312 Moreover, we found main effects for several positive perceptions: mothers with a  
313 stronger perception that their child with a CA was a source of Personal Growth,  
314 Acceptance and Family Cohesion, Happiness and Affection, and Expanded Social  
315 Network presented lower levels of parenting stress, independently of their negative  
316 perceptions. Entering the interaction in the models did not significantly contribute to an  
317 increase in their explained variance, with the exception of the dimension Learning  
318 Through Experience. Post-hoc simple slope analyses revealed a significant association  
319 between negative perceptions and parenting stress among mothers with high ( $b = 1.81$ ,  
320  $SE = 0.48$ ,  $t(39) = 3.79$ ,  $p < .001$ ) and moderate ( $b = 0.95$ ,  $SE = 0.36$ ,  $t(39) = 2.62$ ,  $p =$   
321  $.012$ ) levels of perceptions of Learning through Experience (low levels of positive  
322 perceptions:  $b = 0.09$ ,  $SE = 0.64$ ,  $t(39) = 0.14$ ,  $p = .887$ ). As shown in Figure 1, mothers  
323 with a stronger perception that their children with a CA was a source of Learning  
324 through Experience (high or moderate levels) were found to experience lower levels of

325 parenting stress when their negative perceptions were low. However, these mothers  
326 presented higher levels of parenting stress when they perceived medium to high levels  
327 of negative perceptions; a higher perception of the child as a source of Learning through  
328 Experience functioned as an exacerbator in the relationship between negative  
329 perceptions and stress. Mothers with low levels of positive perceptions tended to present  
330 similar levels of parenting stress, regardless of their negative perceptions.

331

332 [Insert\_Figure\_1\_About\_Here]

333

### 334 **Paternal parenting stress.**

335 Table 6 presents the regression models examining the main and interaction effects of  
336 fathers' negative and positive perceptions on paternal parenting stress.

337 [Insert\_Table\_6\_about\_here]

338

339 For fathers, more negative perceptions also predicted (or marginally predicted)  
340 higher levels of parenting stress. There were no main effects of positive perceptions on  
341 paternal parenting stress, with the exception of the dimension Happiness and Affection.  
342 Entering the interaction in the models contributed to a significant increase in the  
343 explained variance of only one model (i.e., Happiness and Affection). Post-hoc simple  
344 slope analyses showed a significant association between negative perceptions and  
345 parenting stress only when there was a high perception ( $b = 1.02$ ,  $SE = 0.30$ ,  $t(32) =$   
346  $3.46$ ,  $p = .002$ ) that the child with a CA was a source of Happiness and Affection  
347 (medium perception:  $b = 0.47$ ,  $SE = 0.28$ ,  $t(32) = 1.65$ ,  $p = .108$ ; low perception:  $b = -$   
348  $0.09$ ,  $SE = 0.42$ ,  $t(32) = -0.21$ ,  $p = .837$ ). As shown in Figure 2, a higher perception of  
349 the child as a source of Happiness and Affection functioned as a buffer in the

350 relationship between negative perceptions and parenting stress, that is, the levels of  
351 parenting stress were lower, and only increase when fathers display high levels of  
352 perceived burden.

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354 [Insert\_Figure\_2\_About\_Here]

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356

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### Discussion

358

359 This exploratory study produced important findings concerning parental  
360 perceptions associated with the experience of parenting an infant with a CA and the role  
361 of these perceptions on parents' levels of parenting stress. First, our results showed that  
362 both members of the couple presented similar perceptions associated with the childcare  
363 experience, and that negative (perceived burden) and positive (perceived personal  
364 benefits) perceptions may occur independently. Second, more negative perceptions were  
365 associated with higher levels of parenting stress for both mothers and fathers. Third, the  
366 effects of positive perceptions on parents' levels of parenting stress are stronger for  
367 mothers than for fathers, and may occur independently or by interfering in the  
368 relationship between negative perceptions and stress (functioning as an exacerbator for  
369 mothers and as a buffer for fathers).

370

371 The results of this study support the idea of similarity between the maternal and  
372 paternal experience of caring for an infant with a CA. Despite the different gender roles  
373 normally assumed during the transition to parenthood (Katz-Wise et al., 2010), the  
374 increased caregiving demands may lead to a greater paternal involvement in the  
375 caregiving tasks (Huang et al., 2012; Simmerman et al., 2001), when the infant has a

375 CA. Given this shared experience of caregiving, it is possible that both members of a  
376 couple feel the need to communicate more and to share their perceptions and meanings  
377 of their caregiving experience (e.g., difficulties and perceived demands as well as  
378 positive aspects of caring for their child), and thereby influencing each other (Cook &  
379 Kenny, 2005), which results in similar paternal and maternal perceptions.

380         Moreover, and in accordance with previous studies (Hastings, Beck, et al., 2005;  
381 Mak & Ho, 2007), the parents' perception of personal benefits associated with caring  
382 for a child with a CA occurs independently of their levels of perceived burden (negative  
383 perceptions). While the negative perceptions seem to derive more directly from the  
384 objective experience of caregiving, it is possible that the perceived personal benefits  
385 associated with the experience of parenting an infant with a CA may be dependent on  
386 some dispositional characteristics (e.g., dispositional hope, dispositional optimism,  
387 strong sense of self; Affleck & Tennen, 1996; Updegraff & Taylor, 2000), which may  
388 explain the independence of negative and positive perceptions. This hypothesis should  
389 be further examined.

390         In accordance with family stress theories (Boss, 2002), more negative  
391 perceptions about the stressor event were found to predict worse parental adaptation;  
392 both mothers and fathers with higher levels of perceived burden reported higher levels  
393 of parenting stress. The greater perceived negative consequences of caring for an infant  
394 with a CA (e.g., modification of familial and social routines; Baker et al., 2009; Hunfeld  
395 et al., 1999) may translate into higher levels of stress associated with the parenting  
396 experience.

397         Moreover, the perception of personal benefits associated with the childcare  
398 experience was also shown to influence both parents' levels of parenting stress.  
399 However, this influence seems to entail specificities for each gender. For mothers, the

400 perception of their infant with CA as a source of benefits at the interpersonal level (at  
401 the family level, strengthening family relations, and/or at the social level, as a source of  
402 new interpersonal relationships) was associated with lower levels of stress. It is possible  
403 that mothers who perceive more family unity and cohesion (which may be explained by  
404 the mother approaching her nuclear family after the infant's birth, to seek help with the  
405 caregiving tasks; Findler, 2000; Jones & Passey, 2004; Tunali & Power, 2002) and who  
406 perceive the maintenance/development of new social relationships may also perceive  
407 higher availability of social support. The increased availability of support at a time  
408 when it is perceived as needed may help to decrease the isolation that many mothers  
409 describe in the post-diagnosis period (Kerr & McIntosh, 2000), and may be reflected in  
410 better adjustment, as shown in one prior study with this sample (Blind for review).  
411 Additionally, a focus on the child as a source of personal growth and of rewards and  
412 affection despite the demands of the parenting experience also fosters a more positive  
413 and optimistic view of the situation (Dale et al., 2012), allowing the mobilization of  
414 resources (e.g., time, energy, search for information) needed to address the perceived  
415 caregiving demands (Kearney & Griffin, 2001), which translates into better maternal  
416 adaptation.

417         Furthermore, a stronger maternal perception of their infant with a CA as a source  
418 of learning seems to function as an exacerbator in the relationship between perceived  
419 burden and parenting stress. For some mothers, the experience of parenting an infant  
420 with a CA is perceived as a learning opportunity characterized by a greater sensitivity to  
421 the demands and rights of children with special needs. It is possible that these mothers'  
422 increased sensitivity to the child's needs/rights may trigger courtesy stigma (i.e., a  
423 perception that their child with CA is devaluated/discriminated) which may lead to  
424 increased maternal distress (Green, 2003), especially when mothers attempt to meet

425 their child's needs within the context of often poorly coordinated services (Green,  
426 2007). Mothers' feelings of stigma and distress may consequently exacerbate the  
427 relationship between their negative perceptions of caregiving demands and the levels of  
428 parenting stress they experience. However, as this relationship has not been explored  
429 yet, further studies should examine these hypotheses.

430         Different results were found for fathers. Specifically, although fathers reported  
431 levels of personal benefits similar to those of mothers, these perceptions seem to have a  
432 weaker impact on paternal levels of parenting stress, since no main effects of positive  
433 perceptions in paternal parenting stress were found. Thus, for fathers, it is the perceived  
434 burden associated with childcare that has a major role in determining their levels of  
435 parenting stress. In fact, existing research on perceived personal benefits suggests that  
436 benefit finding may be beneficial in some circumstances, but not in others (Affleck &  
437 Tennen, 1996; Zoellner & Maercker, 2006). Therefore, while for mothers the perception  
438 of personal benefits may trigger the mobilization of resources needed to address the  
439 demands of caregiving (e.g., social support, Rychick et al., 2013) in a manner that  
440 reduces their parenting stress levels, this seems not to occur for fathers. Gender  
441 differences on these mechanisms have been scarcely examined, so this hypothesis  
442 should be further explored.

443         Nevertheless, the paternal perception of their infant as a source of affection and  
444 rewarding moments was found to function as a buffer in the relationship between  
445 perceived burden and parenting stress. Fathers who perceive their child as a source of  
446 happiness and affection may experience more positive emotions and more optimism  
447 (Kearney & Griffin, 2001) in the parent-child interactions and when addressing the  
448 perceived demands and burden associated with the caregiving experience, which  
449 translates into lower parenting stress. In fact, these fathers were found to present high

450 levels of parenting stress only when the perceived burden was high, whereas the  
451 remaining fathers reported high stress levels even when they perceived low levels of  
452 burden.

453         Although it constitutes an important contribution to the field, the present study  
454 has some limitations that need to be acknowledged. The first limitation is this study's  
455 reduced power to detect small effects due to sample size, which also influenced the  
456 options concerning statistical analyses (e.g., running separate regression models for  
457 each dimension of positive perceptions). The second limitation is the cross-sectional  
458 design of this study, allowing bidirectional relationships among the study variables.  
459 Although the directionality assigned to the interpretation of our results is supported in  
460 theoretical models (Boss, 2002), this issue should be taken into consideration. The third  
461 limitation is the non-categorical approach to CA (that is, the inclusion of parents of  
462 infants with different types of CA). Although our goal was to examine the common  
463 experience of these parents, future studies should investigate whether these patterns are  
464 similar for parents of infants with different types of CA.

465         Finally, the findings of the present study are clinically relevant. Because  
466 perceptions of the stressor event (i.e., the experience of parenting an infant with a CA)  
467 were found to have an important role in parental adaptation, they should be a major  
468 focus of clinical attention at several levels. First, parents' perceptions (both negative and  
469 positive) should be a target of comprehensive evaluation by mental health professionals.  
470 Second, given couple similarities, the perceptions of both partners should be considered.  
471 The mutual influences within a couple (Cook & Kenny, 2005; Gray, 2003) suggest that  
472 psychological interventions targeting perceptions of the parenting experience should  
473 include both mothers and fathers.

474 Third, parents' perceptions should be taken into account when defining  
475 psychological intervention strategies to promote parental adaptation. Specifically, and  
476 considering the role of negative perceptions in parenting stress, therapeutic strategies  
477 should aim: a) to identify modifiable factors that may be targeted to effectively reduce  
478 the negative impact of caring for a child with a CA (e.g., activation of social support  
479 networks, access to healthcare and education services, parenting skills training); b) to  
480 promote cognitive restructuring of biased negative perceptions about the parenting  
481 experience (e.g., catastrophizing the demands of caregiving; all-or-nothing thinking  
482 when assessing the parenting experience); and c) to foster the use of appropriate coping  
483 strategies to address the parents' perceived burden (e.g., emotion-focused coping  
484 strategies to address the emotional strain of parenting a child with a CA).

485 Furthermore, given the role of positive perceptions in adaptation, particularly for  
486 mothers, psychological intervention should also foster positive perceptions (perception  
487 of personal benefits) concerning the experience of parenting an infant with CA using  
488 strategies such as searching for alternative meanings for the caregiving experience (e.g.,  
489 positive reattributions, benefit finding; Larson, 2010) and planning rewarding parent-  
490 infant interaction activities that allow parents to focus on the child's characteristics that  
491 are not associated with the CA. In sum, the results of this study, although exploratory,  
492 constitute an important contribution to the field, by providing insight into both negative  
493 and positive perceptions associated with the experience of parenting an infant with a  
494 CA.

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## References

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- 499 Abidin, R. (1992). The determinants of parenting behavior. *Journal of Clinical Child*  
500 *Psychology, 21*, 407-412. doi:10.1207/s15374424jccp2104\_12
- 501 Abidin, R. (1995). *Parenting Stress Index* (3<sup>rd</sup> ed.). Odessa: Psychological Assessment  
502 Resources.
- 503 Affleck, G., & Tennen, H. (1996). Construing benefits from adversity: Adaptational  
504 significance and dispositional underpinnings. *Journal of Personality, 64*, 899-  
505 922. doi:10.1111/j.1467-6494.1996.tb00948.x
- 506 Aiken, L. S., & West, S. G. (1991). *Multiple regression: Testing and interpreting*  
507 *interactions*. Newbury Park: Sage.
- 508 Aite, L., Trucchi, A., Nahom, A., Zaccara, A., La Sala, E., & Bagolan, P. (2003).  
509 Antenatal diagnosis of surgically correctable anomalies: Effects of repeated  
510 consultations on parental anxiety. *Journal of Perinatology, 23*, 652-654.  
511 doi:10.1038/sj.jp.7210992
- 512 Albuquerque, S. (2011). *Parents' adaptation to the child's diagnosis of congenital*  
513 *anomaly: Parent's and child's determinants of the individual, relational and*  
514 *parental adjustment*. Unpublished Master Dissertation, University of Coimbra,  
515 Coimbra.
- 516 Albuquerque, S., Fonseca, A., Pereira, M., Nazaré, B., & Canavarro, M. C. (2011).  
517 Estudos psicométricos da versão portuguesa da Escala de Impacto Familiar  
518 (EIF) [Psychometric studies of the portuguese version of the Impact on Family  
519 Scale]. *Laboratório de Psicologia, 9*, 175-189.
- 520 Albuquerque, S., Pereira, M., Fonseca, A., & Canavarro, M. C. (2013). Deficiência e  
521 parentalidade: A influência das perceções de contribuições positivas dos pais na  
522 sobrecarga percebida e qualidade de vida [Disability and parenthood: The role of  
523 parents' perception of positive contributions in the caregiving burden and quality

- 524 of life]. In S. N. Jesus, J. L. Pais-Ribeiro, M. M. Rezende, M. G. Heleno, M. G.  
525 Buela-Casal & J. Tobal (Eds.), *Proceedings of the II Ibero-American Congress/  
526 III Luso-Brazilian Congress of Health Psychology*, Faro, Portugal.
- 527 Baker, S., Owens, J., Stern, M., & Willmot, D. (2009). Coping strategies and social  
528 support in the family impact of cleft lip and palate and parents' adjustment and  
529 psychological distress. *The Cleft Palate - Craniofacial Journal*, 46, 229-236.  
530 doi:10.1597/08-075.1
- 531 Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of  
532 Intellectual Disability Research*, 51, 702-714. doi:10.1111/j.1365-  
533 2788.2007.00960.x
- 534 Behr, S., Murphy, D., & Summers, J. (1992). *User's manual: Kansas Inventory of  
535 Parental Perceptions (KIPP)*. Lawrence: Beach Centre on Families and  
536 Disability.
- 537 Boss, P. (2002). *Family stress management: A contextual approach* (2nd ed.). London:  
538 SAGE.
- 539 Coffey, J. (2006). Parenting a child with chronic illness: A metasynthesis. *Pediatric  
540 Nursing*, 32, 51-59.
- 541 Cook, W., & Kenny, D. (2005). The actor-partner interdependence model: A model of  
542 bidirectional effects in developmental studies. *International Journal of  
543 Behavioral Development*, 29, 101-109. doi:10.1080/01650250444000405
- 544 Crnic, K. A., & Low, C. (2002). Everyday stresses and parenting. In M. Bornstein (Ed.),  
545 *Handbook of parenting: Vol. 5. Practical issues in parenting* (pp. 243-267).  
546 Mahwah: Lawrence Erlbaum Associates.
- 547 Crowley, L. (2010). *An introduction to human disease: Pathology and pathophysiology  
548 correlations* (8th ed.). Sudbury: Jones and Bartlett Publishers.

- 549 Dale, M., Solberg, O., Holmstrom, H., Landolt, M., Eskedal, L., & Vollrath, M. (2012).  
550 Mothers of infants with congenital heart defects: Well-being from pregnancy  
551 through the child's first six months. *Quality of life research*, *21*, 115-122.  
552 doi:10.1007/s11136-011-9920-9
- 553 Deater-Deckard, K. (1998). Parenting stress and child adjustment: Some old hypotheses  
554 and new questions. *Clinical Psychology: Science and Practice*, *5*, 314-332.  
555 doi:10.1111/j.1468-2850.1998.tb00152.x
- 556 Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G\*Power3: A flexible  
557 statistical power analysis program for the social, behavioral, and biomedical  
558 sciences. *Behavior Research Methods*, *39*, 175-191.
- 559 Findler, L. S. (2000). The role of grandparents in the social support system of mothers  
560 of children with a physical disability. *Families in Society*, *81*, 370-381.  
561 doi:10.1606/1044-3894.1033
- 562 Fonseca, A., Nazaré, B., Albuquerque, S., Pereira, M., & Canavarro, M. C. (2013).  
563 Estudos psicométricos da versão portuguesa da Escala de Contribuições  
564 Positivas numa amostra de pais de crianças com anomalia congénita  
565 [Psychometric studies of the portuguese version of the Positive Contributions  
566 Scale in a sample of parents of children with congenital anomalies]. In A.  
567 Pereira, M. Calheiros, P. Vagos, I. Direito, S. Monteiro, C. Silva & A. Allen-  
568 Gomes (Eds.), *Proceedings from the VIII National Symposium of Research in*  
569 *Psychology*. (pp. 83-92). Aveiro: Associação Portuguesa de Psicologia.
- 570 Fonseca, A., Nazaré, B., & Canavarro, M. C. (in press). The role of satisfaction with  
571 social support in perceived burden and stress of parents of six-month-old infants  
572 with a congenital anomaly: Actor and partner effects. *Journal of Child Health*  
573 *Care*. doi:10.1177/1367493513485478

- 574 Gray, D. E. (2003). Gender and coping: The parents of children with high functioning  
575 autism. *Social Science & Medicine*, 56, 631-642. doi:10.1016/S0277-  
576 9536(02)00059-X
- 577 Green, S. (2003). "What do you mean 'what's wrong with her?': stigma and the lives of  
578 families of children with disabilities. *Social Science & Medicine*, 57, 1361-1374.  
579 doi:10.1016/S0277-9536(02)00511-7
- 580 Green, S. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with  
581 a disability. *Social Science & Medicine*, 64, 150-163.  
582 doi:10.1016/j.socscimed.2006.08.025
- 583 Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive  
584 perceptions in mothers of children with intellectual disabilities. *Journal of*  
585 *Applied Research in Intellectual Disabilities*, 15, 269-275. doi:10.1046/j.1468-  
586 3148.2002.00104.x
- 587 Hastings, R. P., Beck, A., & Hill, C. (2005). Positive contributions made by children  
588 with an intellectual disability in the family: Mothers' and fathers' perceptions.  
589 *Journal of Intellectual Disabilities*, 9, 155-165. doi:10.1177/1744629505053930
- 590 Hastings, R. P., Kovshoff, H., Ward, N., Espinosa, F., Brown, T., & Remington, B.  
591 (2005). Systems analysis of stress and positive perceptions in mothers and  
592 fathers of pre-school children with autism. *Journal of Autism and*  
593 *Developmental Disorders*, 35, 635-644. doi:10.1007/s10803-005-0007-8
- 594 Hauser-Cram, P., Warfield, M., Shonkoff, J., & Krauss, M. (2001). Children with  
595 disabilities. *Monographs of the Society for Research in Child Development*, 66,  
596 1-131. doi:10.1111/1540-5834.00160.

- 597 Heiman, T. (2002). Parents of children with disabilities: Resilience, coping and future  
598 expectations. *Journal of Developmental and Physical Disabilities, 14*, 159-171.  
599 doi:10.1023/A:1015219514621
- 600 Huang, Y. P., Chen, S. L., & Tsai, S. W. (2012). Father's experiences of involvement in  
601 the daily care of their child with developmental disability in a Chinese context.  
602 *Journal of Clinical Nursing, 21*, 3287-3296. doi:10.1111/j.1365-  
603 2702.2012.04142.x
- 604 Hunfeld, J., Tempels, A., Passchier, J., Hazebroek, F., & Tibboel, D. (1999). Parental  
605 burden and grief one year after the birth of a child with a congenital anomaly.  
606 *Journal of Pediatric Psychology, 24*, 515-520. doi:10.1093/jpepsy/24.6.515
- 607 Jones, J., & Passey, J. (2004). Family adaptation, coping and resources: Parents of  
608 children with developmental disabilities and behaviour problems. *Journal on*  
609 *Developmental disabilities, 11*, 31-46.
- 610 Jose, P. (2008). ModGraph-I: A programme to compute cell means for the graphical  
611 display of moderational analyses: The internet version, Version 2.0 Retrieved  
612 on February 2012 from [http://www.victoria.ac.nz/psyc/staff/paul-](http://www.victoria.ac.nz/psyc/staff/paul-josefiles/modgraph/modgraph.php)  
613 [josefiles/modgraph/modgraph.php](http://www.victoria.ac.nz/psyc/staff/paul-josefiles/modgraph/modgraph.php).
- 614 Katz-Wise, S., Priess, H., & Hyde, J. (2010). Gender-role attitudes and behavior across  
615 the transition to parenthood. *Developmental Psychology, 46*, 18-28.  
616 doi:10.1037/a0017820
- 617 Kearney, P., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child  
618 with developmental disability. *Journal of Advanced Nursing, 34*, 582-592.  
619 doi:10.1046/j.1365-2648.2001.01787.x

- 620 Kerr, S., & McIntosh, J. (2000). Coping when a child has a disability: Exploring the  
621 impact of parent-to-parent support. *Child: Care, Health & Development*, 26,  
622 309-322. doi:10.1046/j.1365-2214.2000.00149.x
- 623 King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P., & Bates, A.  
624 (2006). A qualitative investigation of changes in the belief systems of families of  
625 children with autism or Down Syndrome. *Child: Care, Health & Development*,  
626 32, 353-369. doi:10.1111/j.1365-2214.2006.00571.x
- 627 Kramer, F. J., Baethge, C., Sinikovic, B., & Schliephake, H. (2007). An analysis of  
628 quality of life in 130 families having small children with cleft lip/palate using  
629 the Impact on Family Scale. *International Journal of Oral and Maxillofacial*  
630 *Surgery*, 36, 1146-1152.
- 631 Laing, S., McMahon, C., Ungerer, J., Taylor, A., Badawi, N., & Spence, K. (2010).  
632 Mother-child interaction and child developmental capacities in toddlers with  
633 major birth defects requiring newborn surgery. *Early Human Development*, 86,  
634 793-800. doi:10.1016/j.earlhumdev.2010.08.025
- 635 Larson, E. (2010). Psychological well-being and meaning-making when caregiving for  
636 children with disabilities: Growth through difficult times or sinking inward.  
637 *OTIR: Occupation, Participation, & Health*, 30, 78-86. doi:10.3928/15394492-  
638 20100325-03
- 639 Locock, L., & Alexander, J. (2006). Just a bystander? Men's place in the process of fetal  
640 screening and diagnosis. *Social Science & Medicine*, 62, 1349-1359.  
641 doi:10.1016/j.socscimed.2005.08.011
- 642 Mak, W., & Ho, G. (2007). Caregiving perceptions of chinese mothers of children with  
643 intellectual disability in Hong Kong. *Journal of Applied Research in Intellectual*  
644 *Disabilities*, 20, 145-156. doi:10.1111/j.1468-3148.2006.00309.x

- 645 Mazer, P., Gischler, S. J., Koot, H. M., Tibboel, D., Dijk, M. v., & Duivenvoorden, H. J.  
646 (2008). Impact of a Child with Congenital Anomalies on Parents (ICCAP)  
647 questionnaire: A psychometric analysis. *Health and Quality of Life Outcomes*, 6,  
648 102-110. doi:10.1186/1477-7525-6-102
- 649 Messias, D., Gilliss, C., Sparacino, P., Tong, E., & Foote, D. (1995). Stories of  
650 transition: Parents recall the diagnosis of congenital heart defect. *Family Systems*  
651 *Medicine*, 13, 367-377. doi:10.1037/h0089280
- 652 Montiroso, R., Fedeli, C., Murray, L., Morandi, F., Brusati, R., Perego, G., & Borgatti,  
653 R. (2012). The role of negative maternal affective states and infant temperament  
654 in early interactions between infants with cleft lip and their mothers. *Journal of*  
655 *Pediatric Psychology*, 37, 241-250. doi:10.1093/jpepsy/jsr089
- 656 Rychick, J., Donaghue, D., Levy, S., Fajardo, C., Combs, J., Zhang, X., ... Diamond, G.  
657 (2013). Maternal psychological stress after prenatal diagnosis of congenital heart  
658 disease. *The Journal of Pediatrics*, 163, 302-307.  
659 doi:10.1016/j.jpeds.2012.07.023
- 660 Santos, S. (2011). *Versão portuguesa do Parenting Stress Index (PSI) - Forma*  
661 *Reduzida: Estudo com uma amostra de mães de crianças com idade inferior a 5*  
662 *anos [Portuguese version of the Parenting Stress Index (PSI) - Short Form:*  
663 *Study with a sample of mothers of children with five years or younger]*. Poster  
664 presented at the VIII Ibero-American Congress of Psychological Evaluation/ XV  
665 International Conference of Psychological Evaluation: Shapes and Contexts,  
666 Lisboa, Portugal.
- 667 Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting  
668 children who have disabilities. *Mental Retardation*, 38, 195-206.  
669 doi:10.1352/0047-6765(2000)038<0195:TOAWPC>2.0.CO;2

- 670 Simmerman, S., Blacher, J., & Baker, B. L. (2001). Fathers' and mothers' perceptions of  
671 father involvement with young children with a disability. *Journal of Intellectual*  
672 *& Developmental Disability*, 26, 325-338. doi:10.1080/13668250120087335
- 673 Smith, T., Oliver, M., & Innocenti, M. (2001). Parenting stress in families of children  
674 with disabilities. *American Journal of Orthopsychiatry*, 71, 257-261.  
675 doi:10.1037/0002-9432.71.2.257
- 676 Stein, R., & Jessop, D. (2003). The Impact on Family Scale revisited: Further  
677 psychometric data. *Journal of Developmental & Behavioral Pediatrics*, 24, 9-16.
- 678 Tunali, B., & Power, T. G. (2002). Coping by redefinition: Cognitive appraisals in  
679 mothers of children with autism and children without autism. *Journal of Autism*  
680 *and Developmental Disorders*, 32, 25-34. doi:10.1023/A:1017999906420
- 681 Updegraff, J., & Taylor, S. (2000). From vulnerability to growth: Positive and negative  
682 effects of stressful life events. In J. Harvey & E. Miller (Eds.), *Loss and*  
683 *trauma: General and close relationship perspectives* (pp. 3-28). Philadelphia:  
684 Brunner-Routledge.
- 685 Uzark, K., & Jones, K. (2003). Parenting stress and children with heart disease. *Journal*  
686 *of Pediatric Health Care*, 17, 163-168. doi:10.1067/mps.2003.22
- 687 World Health Organization. (1992). *International Classification of Diseases 10<sup>th</sup>*.  
688 Geneva: World Health Organization.
- 689 Zoellner, T., & Maercker, A. (2006). Posttraumatic growth in clinical psychology: A  
690 critical review and introduction of a two component model. *Clinical Psychology*  
691 *Review*, 26, 626-653. doi:10.1016/j.cpr.2006.01.008
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Table 1 – Sample sociodemographic and clinical characteristics (obstetric history).

	Mothers ( <i>n</i> = 43)	Fathers ( <i>n</i> = 36)	
<i>Sociodemographic characteristics</i>			
	<i>M (SD)</i>	<i>M (SD)</i>	<i>t</i>
<i>Age</i>	31.58 (4.95)	33.25 (5.05)	-1.48
<i>Educational level (years)</i>	14.07 (3.53)	12.11 (2.73)	2.69**
	<i>n (%)</i>	<i>n (%)</i>	$\chi^2$
<i>Marital status</i>			
Married/Living together	40 (93.0)	34 (94.4)	0.20
Single/Divorced	3 (7.0)	2 (5.6)	
<i>Professional status</i>			
Employed	35 (81.4)	33 (91.7)	1.73
Unemployed	8 (18.6)	3 (8.3)	
<i>Obstetric history</i>			
<i>Parity</i>			
Primiparity	22 (51.2)		
Multiparity	21 (48.8)		
<i>History of pregnancy loss</i>			
Yes	8 (18.6)		
No	35 (81.4)		

\*\**p* < .01.

Table 2 – Infant’s clinical information.

Infants ( <i>n</i> = 43)	
<i>n</i> (%)	
<i>Timing of diagnosis</i>	
Prenatal	26 (60.5)
Postnatal	17 (39.5)
<i>Type of congenital anomaly</i>	
Congenital heart disease	16 (37.2)
Nervous system anomalies	5 (11.6)
Digestive system anomalies	4 (9.3)
Urinary system anomalies	11 (25.6)
Oro-facial clefts	4 (9.3)
Limb anomalies	3 (7.0)
<i>Hospitalization</i>	
Yes	19 (44.2)
No	24 (55.8)
<i>Need for surgery</i>	
Yes	13 (30.2)
No	30 (69.8)

Table 3 – Descriptive statistics of negative (perceived burden) and positive (perceived personal benefits) perceptions and parenting stress

	Mothers	Fathers
	( <i>n</i> = 36)	( <i>n</i> = 36)
	<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )
Impact on Family Scale, IOF-R (Negative perception/Perceived Burden)	25.56 (8.23)	25.61 (8.26)
Personal Growth & Future Awareness, PCS Dimension 1 (Positive perception/Benefit 1)	2.88 (0.55)	2.86 (0.42)
Learning Trough Experience, PCS Dimension 2 (Positive perception/Benefit 2)	2.65 (0.52)	2.54 (0.42)
Acceptance & Family Cohesion, PCS Dimension 3 (Positive perception/Benefit 3)	3.03 (0.50)	3.00 (0.41)
Happiness & Affection, PCS Dimension 4 (Positive perception/Benefit 4)	3.61 (0.59)	3.62 (0.41)
Expanded Social Netwoek, PCS Dimension 6	2.32 (0.52)	2.27 (0.45)

(Positive perception/Benefit 6)

Parenting Stress, PSI-SF

64.86 (20.10)

61.86 (14.89)

(Dependent measure)

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Table 4 –Pearson correlations between sociodemographic and clinical variables, negative (perceived burden) and positive (perceived personal benefits) perceptions and parenting stress

	1	2	3	4	5	6	7	8	9	10	11	12	13
1.Age	--	-.13	-.48**	.30*	-.08	-.12	-.09	-.40**	-.25	-.10	-.24	-.01	.17
2.Educational level	-.27	--	.09	.01	-.05	.02	-.24	-.29	-.32*	-.27	-.04	-.33*	-.04
3.Parity	-.47**	.26	---	-.54**	.07	-.16	-.29	.34*	.02	.07	.07	-.03	.07
4.Timing diagnosis	.39*	-.29	-.57***	---	.09	.14	.19	-.31*	.07	-.15	-.21	-.15	.16
5.Hospitalization	.05	.05	-.02	.04	---	.74***	.36*	-.09	.37*	.18	.03	.35*	.03
6. Need of surgery	.05	.02	-.06	.05	.74***	----	.54**	-.14	.25	-.01	-.15	.14	.16
7.Negative perceptions/ Perceived burden	-.01	-.26	-.28	.15	.35*	.42**	---	-.01	.36*	.09	.14	.21	.46**
8. Positive perception 1	-.12	-.35*	.03	.04	-.13	-.11	.04	---	.49**	.75***	.66***	.47**	-.22
9. Positive perception 2	.17	-.51**	-.39	.61	.15	.13	.23	.45**	---	.57***	.39**	.34*	.14
10. Positive perception 3	-.18	-.24	.01	.22	-.03	.01	.00	.69***	.61***	---	.75***	.49**	-.36*
11. Positive perception 4	-.21	.22	.01	.09	-.13	-.39	-.23	.24	.04	.35*	---	.76***	-.39*

12. Positive perception 6	.29	-.59***	-.14	.38*	.02	.00	.01	.46**	.60***	.40*	-.09	---	-.25
13. Dependent measure/ Parenting Stress	.15	-.26	.11	.13	.10	.28	.46**	-.09	.28	-.16	-.54*	-.02	---

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\* $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$

*Note.* The correlation matrix concerning mother's ( $n = 43$ ) variables is above the diagonal and the correlational matrix concerning father's ( $n = 36$ ) variables is below the diagonal.

Table 5 – Effects of perceived burden and perceived personal benefits on maternal stress: main and interaction effects ( $n = 43$ )

<i>Maternal stress</i>			
<i>(n = 43)</i>			
<b>Positive perception/Benefit 1</b>	Step 1:	Step 2:	Step 3:
	$\Delta R^2 = .05, F_{2,40} = 0.98$	$\Delta R^2 = .27, F_{2,38} = 7.64^{***}$	$\Delta R^2 = .02, F_{1,37} = 0.67$
	<i>B (SE)</i>	<i>B (SE)</i>	<i>B (SE)</i>
Hospitalization	-8.42 (9.18)	-6.34 (7.98)	-6.37 (8.06)
Surgery	13.77 (9.93)	-1.72 (9.61)	-1.38 (9.74)
Perceived burden		1.23 (0.40)**	1.30 (0.41)**
Personal Growth		-11.02 (5.01)*	-8.58 (7.53)
P. burden x P. Growth			0.36 (0.83)
Overall model statistic: $F_{5,37} = 3.54, p = .01, R^2 = .32$			
<b>Positive perception/Benefit 2</b>	Step 1:	Step 2:	Step 3:
	$\Delta R^2 = .05, F_{2,40} = 0.98$	$\Delta R^2 = .19, F_{2,38} = 4.63^*$	$\Delta R^2 = .10, F_{1,35} = 5.64^*$

	<i>B (SE)</i>	<i>B (SE)</i>	<i>B (SE)</i>
Hospitalization	-8.42 (9.18)	-6.87 (8.94)	-7.24 (8.44)
Surgery	13.77 (9.93)	0.44 (10.32)	-4.16 (9.93)
Perceived burden		1.27 (0.44)**	-4.22 (2.35)†
Learning through Experience		0.60 (6.32)	11.44 (7.51)
P. burden x Learning thr Exp.			2.02 (0.85)*
Overall model statistic: $F_{5,37} = 3.72, p = .008, R^2 = .34$			
<b>Positive Perception/Benefit 3</b>	Step 1:	Step 2:	Step 3:
	$\Delta R^2 = .05, F_{2,40} = 0.98$	$\Delta R^2 = .34, F_{2,38} = 10.48^{***}$	$\Delta R^2 = .00, F_{1,37} = 0.01$
	<i>B (SE)</i>	<i>B (SE)</i>	<i>B (SE)</i>
Hospitalization	-8.42 (9.18)	0.72 (7.95)	0.74 (8.05)
Surgery	13.77 (9.93)	-7.41 (9.43)	-7.32 (9.60)
Perceived burden		1.45 (0.38)**	1.45 (0.39)**
Acceptance & Family Cohesion		-16.62 (5.41)**	-15.64 (10.99)
P. burden x Accep. & Fam. Coh.			0.13 (1.24)

Overall model statistic: $F_{5,37} = 4.65, p = .002, R^2 = .39$			
<b>Positive perception/Benefit 4</b>	Step 1:	Step 2:	Step 3:
	$\Delta R^2 = .05, F_{2,40} = 0.98$	$\Delta R^2 = .29, F_{2,38} = 8.20^{**}$	$\Delta R^2 = .00, F_{1,37} = 0.01$
	<i>B (SE)</i>	<i>B (SE)</i>	<i>B (SE)</i>
Hospitalization	-8.42 (9.18)	-2.41 (8.08)	-2.41 (8.19)
Surgery	13.77 (9.93)	-4.71 (9.69)	-4.80 (9.90)
Perceived burden		1.23 (0.39) <sup>**</sup>	1.22 (0.41) <sup>**</sup>
Happiness & Affection		-11.39 (4.75) <sup>*</sup>	-11.60 (5.78) <sup>†</sup>
P. burden x Happ. & Affect.			-0.04 (0.60)
Overall model statistic: $F_{5,37} = 3.71, p = .008, R^2 = .33$			
<b>Positive perception/Benefit 6</b>	Step 1:	Step 2:	Step 3:
	$\Delta R^2 = .05, F_{2,40} = 0.98$	$\Delta R^2 = .30, F_{2,38} = 8.60^{**}$	$\Delta R^2 = .04, F_{1,37} = 2.61$
	<i>B (SE)</i>	<i>B (SE)</i>	<i>B (SE)</i>
Hospitalization	-8.42 (9.18)	1.59 (8.48)	0.26 (8.34)
Surgery	13.77 (9.93)	-6.02 (9.72)	-7.09 (9.54)

Perceived burden	1.49 (0.40) **	1.24 (0.42) **
Expanded Social Network	-14.38 (5.69) *	-5.47 (7.84)
P. burden x Exp. Social Net.		1.36 (0.84)

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Overall model statistic:  $F_{5,37} = 4.70, p = .002, R^2 = .39$

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†  $p < .10$ , \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$ .

Table 6 – Effects of perceived burden and perceived personal benefits on paternal stress: main and interaction effects ( $n = 36$ )

<i>Paternal stress</i>			
<i>(n = 36)</i>			
<b>Positive perception/Benefit 1</b>	Step 1:	Step 2:	Step 3:
	$\Delta R^2 = .10, F_{2,33} = 1.98$	$\Delta R^2 = .14, F_{2,31} = 2.97^\dagger$	$\Delta R^2 = .03, F_{1,30} = 1.43$
	<i>B (SE)</i>	<i>B (SE)</i>	<i>B (SE)</i>
Hospitalization	-6.20 (7.44)	-7.36 (7.07)	-6.60 (7.05)
Surgery	14.69 (8.03) <sup>†</sup>	9.66 (7.86)	9.64 (7.81)
Perceived burden		0.78 (0.32)*	0.64 (0.34) <sup>†</sup>
Personal Growth		-1.13 (5.85)	-0.84 (5.82)
P. burden x P. Growth			0.90 (0.75)
Overall model statistic: $F_{5,30} = 2.39, p = .061, R^2 = .29$			
<b>Positive perception/Benefit 2</b>	Step 1:	Step 2:	Step 3:
	$\Delta R^2 = .10, F_{2,33} = 1.98$	$\Delta R^2 = .18, F_{2,31} = 3.56^*$	$\Delta R^2 = .00, F_{1,30} = 0.01$

	<i>B (SE)</i>	<i>B (SE)</i>	<i>B (SE)</i>
Hospitalization	-6.20 (7.44)	-7.69 (6.95)	-7.57 (7.33)
Surgery	14.69 (8.03) <sup>†</sup>	10.20 (7.75)	10.16 (7.91)
Perceived burden		0.66 (0.33) <sup>*</sup>	0.65 (0.38) <sup>†</sup>
Learning through Experience		6.11 (6.06)	6.23 (6.46)
P. burden x Learning thr Exp.			0.05 (0.83)
Overall model statistic: $F_{5,30} = 2.26, p = .074, R^2 = .27$			
<b>Positive perception/Benefit 3</b>	Step 1:	Step 2:	Step 3:
	$\Delta R^2 = .10, F_{2,33} = 1.98$	$\Delta R^2 = .16, F_{2,31} = 3.40^*$	$\Delta R^2 = .02, F_{1,30} = 0.98$
	<i>B (SE)</i>	<i>B (SE)</i>	<i>B (SE)</i>
Hospitalization	-6.20 (7.44)	-7.56 (6.98)	-5.37 (7.32)
Surgery	14.69 (8.03) <sup>†</sup>	10.04 (7.78)	8.53 (7.93)
Perceived burden		0.77 (0.32) <sup>*</sup>	0.61 (0.36) <sup>†</sup>
Acceptance & Family Cohesion		-5.02 (5.81)	-3.63 (5.98)
P. burden x Accep. & Fam. Coh.			0.77 (0.77)

Overall model statistic: $F_{5,30} = 2.46, p = .055, R^2 = .29$			
<b>Positive perception/Benefit 4</b>	Step 1:	Step 2:	Step 3:
	$\Delta R^2 = .10, F_{2,33} = 1.98$	$\Delta R^2 = .30, F_{2,31} = 7.91^{**}$	$\Delta R^2 = .08, F_{1,30} = 4.35^*$
	<i>B (SE)</i>	<i>B (SE)</i>	<i>B (SE)</i>
Hospitalization	-6.20 (7.44)	-2.23 (6.50)	-1.13 (6.19)
Surgery	14.69 (8.03) <sup>†</sup>	0.50 (7.68)	-0.88 (7.32)
Perceived burden		0.69 (0.28) <sup>*</sup>	0.51 (0.28) <sup>†</sup>
Happiness & Affection		-16.99 (5.89) <sup>**</sup>	-21.25 (5.95) <sup>**</sup>
P. burden x Happ. & Affect.			1.36 (0.63) <sup>*</sup>
Overall model statistic: $F_{5,30} = 5.62, p = .001, R^2 = .48$			
<b>Positive perception/Benefit 6</b>	Step 1:	Step 2:	Step 3:
	$\Delta R^2 = .10, F_{2,33} = 1.98$	$\Delta R^2 = .14, F_{2,31} = 2.95^{\dagger}$	$\Delta R^2 = .00, F_{1,30} = 0.14$
	<i>B (SE)</i>	<i>B (SE)</i>	<i>B (SE)</i>
Hospitalization	-6.20 (7.44)	-7.25 (7.05)	-7.35 (7.16)
Surgery	14.69 (8.03) <sup>†</sup>	9.72 (7.86)	9.67 (7.98)

Perceived burden	0.77 (0.32)*	0.77 (0.32)*
Expanded Social Network	0.11 (5.35)	-0.40 (5.60)
P. burden x Exp. Social Net.		-0.24 (0.64)

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Overall model statistic:  $F_{5,30} = 2.04, p = .098, R^2 = .25$

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†  $p < .10$ , \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$ .