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Clinical determinants of parents' emotional reactions to the disclosure of a diagnosis of congenital anomaly

Ana Fonseca, Bárbara Nazaré, & Maria Cristina Canavarro

Abstract

Objective: To examine the variability of parents' patterns of emotional reactions (high intensity vs. low intensity) and of the intensity of each emotion when a prenatal or postnatal diagnosis of a congenital anomaly is disclosed, as a function of gender and clinical variables (diagnosis characteristics and obstetric history). Design: Cross-sectional study. Setting: Two urban Portuguese hospitals. **Participants:** The parents (60 mothers and 50 fathers) of 60 infants prenatally or postnatally diagnosed with a congenital anomaly. Methods: One month after the disclosure of the diagnosis, the parents answered questionnaires regarding sociodemographic and clinical variables and their emotional experience at the disclosure. **Results:** Gender differences in the parents' emotional reactions were not found, and intra-couple congruence was frequent. When there was uncertainty regarding the diagnosis, no prior knowledge about the diagnosis (for fathers only), and no history of pregnancy loss (for mothers only), parents presented significantly more frequently with a pattern of high intensity negative emotional reactions to the disclosure. Type of congenital anomaly, timing of diagnosis, and parity were not found to be significantly associated with the patterns of emotional reactions, but differences in the intensity of specific emotions were found for all variables. **Conclusion:** Both parents' emotional experience should be acknowledged at the disclosure. Clinical variables were found to define the stressful situation (the diagnosis). When the diagnosis was perceived as more threatening (i.e., more unexpected, less controllable and predictable), parents presented a pattern of high intensity emotional reactions.

Key-words: clinical variables; congenital anomaly; disclosure; gender differences; parental emotional reactions; prenatal diagnosis; postnatal diagnosis.

Callouts:

Callout 1: Parents' emotional reactions at the disclosure of a diagnosis of a congenital anomaly were found to be predictive of parents' subsequent adjustment.

Callout 2: The unexpectedness and ambiguity of the diagnosis lead to parents' high intensity negative emotional reactions when they first learn of their infant's congenital anomaly.

Callout 3: Parents should be encouraged to share their appraisal of the diagnosis of a congenital anomaly (stressor event) with each other and with health professionals.

Introduction

Congenital anomalies are the leading cause of infant mortality and morbidity (Milunsky & Milunsky, 2010). In Portugal, 119 cases of live births with an identifiable congenital anomaly per 10,000 live births were reported in 2009 (European Surveillance of Congenital Anomalies [EUROCAT], n.d.), with only 50.7% being identified during the prenatal period (Instituto Nacional de Saúde Doutor Ricardo Jorge, 2011). The disclosure of a diagnosis of a congenital anomaly (DCA) is frequently shocking and disrupts the existing parental representations of a perfect and healthy baby (Aite, Zaccara, Nahom et al., 2006), triggering a set of mostly negative emotional reactions in both parents (Statham, Solomou, & Chitty, 2000).

Most existing research has identified a pattern of acute grief reactions in response to the DCA (Statham et al., 2000), characterized by highly intense negative emotions – shock, anxiety, sadness, anger, guilt, despair, and frustration (Chaplin, Schwitzer, & Perkoulidis, 2005; Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975). In addition, few studies mention the presence of positive emotions such as relief (Petrucelli, Walker, & Schorry, 1998) and hope (Sommerseth & Sundby, 2010). Research shows that both mothers and fathers feel the same emotions at the disclosure; although fathers presented less intense negative emotional reactions than did mothers in some studies (Kerr & McIntosh, 1998; Schuth, Karck, Wilhelm, & Reisch, 1994), others found no gender differences (Fonseca, Nazaré, & Canavarro, 2011a).

Despite the description of a common pattern of acute grief reactions to the disclosure of a DCA, some studies have also highlighted the variability of parents' emotional reactions, that is, the possibility that different parents experience distinct emotional reactions (Statham et al., 2000). In fact, a previous study identified two distinct patterns of parental emotional reactions to the disclosure of a DCA: a pattern of high-intensity negative emotional reactions, which fits the pattern of acute grief reactions described in the literature, and a pattern

characterized by low-intensity negative emotional reactions. These two patterns differed with respect to the intensity of negative emotions but were similar with regard to the intensity of positive emotions (Fonseca et al., 2011a). As the pattern of high-intensity negative emotional reactions at the disclosure was found to be predictive of both parents' psychopathological symptoms six months after the infant's birth (Fonseca, Nazaré, & Canavarro, 2011b), it is important to examine the variability of the parents' emotional reactions when a DCA is disclosed.

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Research on this topic has been primarily descriptive, so knowledge is scarce about the factors underlying the variability of parents' emotional reactions to the disclosure of a DCA. In this study, we focused on the variability of these reactions as a function of several clinical variables (DCA characteristics and obstetric history), because these variables are important in defining the stressful situation (Boss, 2002; Rolland, 1999), that is, the occurrence of a DCA.

When considering the characteristics of the DCA, results suggest that parents' emotional reactions do not vary as a function of type of congenital anomaly; although the studies did not specifically aim to examine this question, the emotions described were similar whether the samples included several types of congenital anomaly (Drotar et al., 1975; Lalor, Begley, & Galavan, 2009; Mitchell, 2004) or just a single specific congenital anomaly (e.g., sex chromosome abnormalities, Petrucelli et al., 1998; cleft lip and palate, Beaumont, 2006). Aite, Zaccara, Nahom et al. (2006) found that the type of congenital anomaly was not related to the presence of negative emotions (sadness, anxiety and anger) in mothers following the disclosure of the diagnosis. However, one study found that parents of infants with congenital heart disease felt higher anxiety, while parents of infants diagnosed with Down syndrome reacted primarily with shock, suggesting that some variability may occur as a function of type of congenital anomaly (Garwick, Patterson, Bennett, & Blum, 1995).

Moreover, the parental emotional reactions to the DCA were similar whether the DCA was disclosed during pregnancy or after the infant's birth (Aite, Zaccara, Nahom et al., 2006; Beaumont, 2006; Nusbaum et al., 2008). However, when the diagnosis is prenatal, parents may receive less information (e.g., treatment options, often available only after the infant's birth; Statham et al., 2000), which may intensify their anxiety, despair and frustration when the diagnosis is disclosed. On the other hand, as parents may feel reassured about the infant's health due to normal prenatal examinations (Aite et al., 2003), the postnatal DCA may be perceived as more unexpected for parents, leading to more intense reactions of shock.

Often, when parents first learn of their infant's DCA, they have no prior knowledge about the diagnosis. When the DCA is disclosed, they are faced with a great deal of new and sometimes difficult-to-understand information, which can intensify their reactions of anxiety and shock (Aite et al., 2004; Aite, Zaccara, Trucchi et al., 2006).

Furthermore, the degree of uncertainty associated with the DCA and its prognosis is also an important DCA characteristic, because it is associated with the inability to determine the meaning of illness-related events and can influence the individual's psychological adaptation (Mishel, 1988, 1990). Research has shown that when great diagnostic uncertainty is perceived, mothers tend to report more difficulties in attaching meaning to the diagnosis (Lalor, Begley, & Galavan, 2008; Lalor et al., 2009) and manifest greater levels of anxiety (Kemp, Davenport, & Pernet, 1998). Aite et al. (2009) found that maternal anxiety after a prenatal DCA was associated more strongly with the uncertainty regarding the clinical development and prognosis rather than with the objective medical severity of the DCA, suggesting that a great degree of uncertainty may be related to high-intensity negative emotional reactions.

Finally, obstetric history can also be considered an important factor in the variability of emotional reactions. To our knowledge, the effect of parity has not been investigated.

However, women with a previous healthy pregnancy may be more confident about the infant's health, leading to greater unexpectedness of the DCA (Lalor & Begley, 2006) and, thus, more intense negative emotional reactions. Additionally, a history of pregnancy loss has been associated with more frequent reactions of sadness and anger when the diagnosis is disclosed (Aite, Zaccara, Nahom et al., 2006), which may be related to the cumulative effect of negative reproductive experiences within the couple. However, prior negative reproductive experiences may be associated with more highly negative expectations regarding the current pregnancy and infant's health (e.g., DeBackere, Hill, & Kavanaugh, 2008), which may lead to less shocking reactions when a DCA is disclosed.

Conceptual framework

The occurrence of a DCA may be a stressful event for the family, as it affects the entire family system (Boss, 2002; Seligman & Darling, 2007). As the detrimental effects of intra-couple incongruent reactions to stressful events are well-documented (Marshak & Prezant, 2007), it is essential to examine the effects of the occurrence of a DCA in both parents, as well as the intra-couple congruence in emotional reactions.

In addition, according to the Family Stress Adaptation Theory (Boss, 2002), the familial response to a stressor event depends on its characteristics, the family's perception of the event, and the family's resources. The characteristics of the stressor event include the degree to which it is normative and predictable (e.g., transition to parenthood) or unexpected (e.g., illness in one family member) or the degree to which it is clear or ambiguous (facts about the situation are unavailable or unclear; Boss, 2002). Depending on these characteristics, family members build a perception of the event as more or less threatening, which may influence their emotional responses and the resources and coping strategies activated by them to address the stressor event (Boss, 2002).

Given this conceptual framework, the present study aimed to: 1) investigate gender

differences and intra-couple congruence in the emotional reactions to the disclosure of a DCA; 2) examine the variability of the maternal and paternal emotional reactions as a function of the characteristics of the stressor event, that is, clinical variables (DCA characteristics – type of congenital anomaly, timing of DCA, prior knowledge of the DCA, and uncertainty regarding the DCA; couple's obstetric history – parity, history of pregnancy loss). The variability of parents' emotional reactions to the disclosure of a DCA was analyzed in terms of both the patterns of intensity of negative emotional reactions (high vs. low) and the intensity of the different emotions.

We established the following hypotheses: 1) Mothers and fathers will present similar and congruent emotional reactions within the couple; 2) The parents' emotional reactions will not vary as a function of type of congenital anomaly; 3) The parents' emotional reactions will not vary as a function of timing of the DCA; 4) Parents with no prior knowledge about the DCA will present more intense negative emotional reactions than will parents with prior knowledge about the DCA; 5) Parents who perceive uncertainty regarding the DCA will present more intense negative emotional reactions than will parents who perceive certainty regarding the DCA; 6) Parents with previous children will present more intense negative emotional reactions than will parents with no previous children. No hypothesis was presented for history of pregnancy loss, given the inconsistency of the existing results.

Methods

Procedure and participants

This study was approved by the Ethics Committees of two Portuguese hospitals (Hospitals da Universidade de Coimbra and Centro Hospitalar de Coimbra). The inclusion criteria for this study were as follows: having an infant with a prenatally or postnatally reported DCA, without the occurrence of perinatal death or without the legal possibility of terminating the pregnancy; being at least 18 years old; and having a literacy level that allowed for the

comprehension of the assessment protocol. The sample collection took place between September 2009 and September 2011. Approximately one month (M = 34.23 days) after the disclosure of the DCA, all parents were informed of this investigation by the medical team at the end of a medical appointment and their authorization was sought to be contacted personally by the researchers. Consecutive sampling was used; all accessible subjects who met the inclusion criteria were included. The research goals were presented to all contacted parents, and an informed consent form was signed by those parents who agreed to participate. The informed consent offered information on the following: 1) the research goals; 2) the voluntary nature of participation in the study, free of charge; 3) the possibility of withdrawing from the study without affecting their medical care; and 4) the guarantee of confidentiality. The participants were then given the questionnaires and were asked to return them to the researchers at their next medical appointment.

The researchers invited 82 couples, of which 22 refused to participate or did not return the questionnaires (participation rate = 73.2%; average time until return: M = 22.97 days, SD = 13.63). The questionnaires were returned only by women in 10 cases (16.7%). The sample was comprised of parents of 60 infants with a prenatal or postnatal DCA – 60 (54.5%) mothers and 50 (45.5%) fathers. The socio-demographic and clinical characteristics are presented in Table 1. Mothers and fathers had similar socio-demographic characteristics with the exception of educational level: mothers had a higher educational level than did fathers.

Measures

The participants completed a socio-demographic form soliciting gender, age, marital status, educational level, and professional status and a clinical information form. The clinical information form asked about obstetric history (parity and history of pregnancy loss) and about DCA characteristics, namely: a) type of congenital anomaly; b) timing of the DCA; c)

prior knowledge about the DCA ("Have you ever heard of the congenital anomaly diagnosed in your infant?", yes or no); d) degree of certainty regarding the DCA ["What was the certainty level of your infant's diagnosis?" with four response options which were grouped by the researchers in two categories – certainty ("both the DCA and its prognosis were well identified") and uncertainty ("the DCA was well identified, but there was no absolute certainty regarding its prognosis (although the main consequences were identified); the DCA was well identified, but there was no absolute certainty regarding the DCA or its prognosis")].

Congenital anomalies were categorized according to the EUROCAT Categorization scheme (EUROCAT, 2009). Given the low frequency of some congenital anomalies in our sample, and for purposes of analyses, the congenital anomalies were grouped into four categories: congenital heart diseases, urinary system anomalies, visible malformations (orofacial clefts and limb anomalies), and other anomalies (digestive system and nervous system anomalies).

Emotional reactions to the diagnosis were evaluated with the question used by Petrucelli et al. (1998): "When you learned of your infant's diagnosis, how much did you feel the following emotions?". However, instead of an ordinal scale, we adopted visual analogue scales (from 0 = I did not feel it at all to 100 = I felt it a lot), to assess the presence and magnitude of several emotions at a given time. A visual analogue scale is a horizontal line of a given length (usually 100 mm) with verbal labels at each extreme; participants mark the position on the line that best describes their response, and the distance from the beginning of the line to the participant's mark is used as their score. The list of emotions was chosen based on a literature review of emotional reactions to a DCA (Fonseca & Canavarro, 2010). Ten emotions were listed (negative: guilt, anger, sadness, anxiety, shock, despair, shame, frustration; and positive: relief, hope). The alpha coefficient in our sample was .81.

Data Analyses

Analyses were conducted with SPSS, v. 19.0. Descriptive statistics were used for characterization purposes. Socio-demographic characteristics of mothers and fathers were compared with *t*-tests (continuous variables) and chi-squared tests (categorical variables).

The participants' classification into the two patterns of emotional reactions ("high-intensity negative emotional reactions" and "low-intensity negative emotional reactions"; Fonseca et al., 2011a), was performed with a K-means cluster analysis, asking for a two-cluster solution. This technique of cluster analysis is called for when there are prior hypotheses regarding the number of clusters to form.

Regarding the first hypothesis, chi-squared tests were used to examine gender differences in the patterns of emotional reactions. To analyze intra-couple congruence, the frequency of cases in which both partners within the couple had congruent or incongruent patterns of emotional reactions was calculated. To examine gender differences regarding the intensity of the different emotions, a repeated-measures MANOVA was used (with gender as a within-subjects factor), followed by univariate ANOVAs. Intra-couple congruence in the intensity of the different emotions was examined using bivariate Pearson correlations.

Regarding the remaining hypotheses, we used chi-squared tests to examine the variability of the patterns of emotional reactions as a function of the different clinical variables. When considering the intensity of the different emotions, differences were examined using the Kruskal-Wallis test (for the type of congenital anomaly, followed by post-hoc Mann-Whitney tests with Bonferroni correction when the effect was significant) and Mann-Whitney tests (for the remaining variables). Non-parametric tests were used because the necessary assumptions for using parametric tests were not met. Because of the interdependence of the intra-couple observations, which could bias the results, these analyses were conducted separately for mothers and fathers.

Significance was defined as p < .05, but marginally significant effects (p < .10) are also reported. Post-hoc calculations for the comparison analyses performed with a significance level of .10 and power \geq .80 indicated that small effects (f \geq .17) could be detected with MANOVA and medium to large effects (d \geq .57) could be detected with non-parametric tests (Faul, Erdfelder, Lang, & Buchner, 2007).

Results

Gender differences and intra-couple congruence of emotional reactions to the disclosure of a DCA

Individuals were clustered in the "high-intensity negative emotional reactions" cluster or in the "lower-intensity negative emotional reactions" cluster, based on their emotional reactions. Table 2 presents the cluster membership and the average intensity of the different emotions felt by mothers and fathers when the DCA was disclosed. As shown in Table 2 and confirming our first hypothesis, there were no gender differences in the percentage of male and female participants within each cluster. Within the couple, in 72% (n = 36) of cases both partners had similar patterns of emotional reactions, suggesting intra-couple congruent emotional reactions; of these cases, both partners presented high intensity negative emotional reactions in 18 (50%) cases.

The multivariate effect of gender on the intensity of the different emotions was also not significant (Pillai's Trace = .311, $F_{10,40}$ = 1.67, p = .126, η^2 = .311). Univariate tests showed that mothers presented only higher levels of guilt than did fathers. The intensity of the maternal and paternal emotions was significantly but only moderately correlated (r-values ranged from .25 to .54).

[Insert_Table_2_about_here]

Clinical variables as correlates of maternal and paternal emotional reactions to the disclosure of a DCA

Next, the variability of parents' emotional reactions as a function of clinical variables was explored. Analyses were conducted separately for mothers and fathers.

Type of congenital anomaly

The type of congenital anomaly was not significantly associated with the maternal (χ^2 = 1.87, p = .600) or paternal (χ^2 = 2.47, p = .481) patterns of emotional reactions to the disclosure of a DCA, confirming our second hypothesis. However, when considering the intensity of the different emotions, some differences were found as a function of the type of congenital anomaly. For mothers, the type of congenital anomaly was associated with significant differences in the intensity of the following emotions: guilt ($\chi^2 = 9.52$, p = .023), anger ($\chi^2 = 9.41$, p = .023), and sadness ($\chi^2 = 8.98$, p = .03). Post-hoc analyses showed that mothers whose infants were diagnosed with a urinary system anomaly showed significantly more anger (M = 45.6, SD = 43.9) than did mothers whose infants were diagnosed with a congenital heart disease (M = 11.7, SD = 31.4, Z = -2.68, p = .007) and significantly more guilt (M = 54.5, SD = 36.7) than did mothers whose infants were diagnosed with a visible malformation (M = 11.2, SD = 25.4; Z = -2.85, p = .004). In addition, mothers whose infants were diagnosed with a visible malformation felt significantly less sadness (M = 55.2, SD =41.4) than did mothers whose infants were diagnosed with other malformations (M = 95.0, SD= 10.3; Z = -2.84, p = .004). Conversely, the type of congenital anomaly was not associated with significant differences in the intensity of the different emotions, for fathers.

Timing of the DCA

Confirming our third hypothesis, the timing of the DCA (prenatal vs. postnatal) was not significantly associated with the maternal ($\chi^2 = 1.41$, p = .235) or paternal ($\chi^2 = 0.64$, p = .423) patterns of emotional reactions to the disclosure of a DCA. However, when considering

the intensity of the different emotions, we found some differences for mothers only. Mothers who learned of their infant's DCA during the prenatal period felt significantly more anger (M = 36.1, SD = 40.9; Z = -2.87, p = .004) and sadness (M = 88.1, SD = 23.5, Z = -2.01, p = .044) than mothers whose infant's DCA was disclosed after birth (anger: M = 6.79, SD = 22.8; sadness: M = 71.5, SD = 36.3). On the other hand, for fathers, no significant differences were found in the intensity of the different emotions as a function of the timing of the DCA.

Prior knowledge about the DCA

Table 3 presents the frequency of patterns of emotional reactions and the average intensities of the different emotions as a function of having or not having prior knowledge about the DCA. As shown in Table 3, our fourth hypothesis was only confirmed for fathers: they presented a pattern of high-intensity negative emotional reactions more frequently when they had no prior knowledge of the DCA; no significant effect was found for mothers.

However, some differences were found for mothers and fathers when considering the intensities of the different emotions. As shown in Table 3, mothers who had prior knowledge about the DCA felt significantly more guilt and frustration than did mothers who had no prior information about the DCA. On the other hand, the fathers who had prior knowledge about the DCA presented significantly less intense shock than did fathers who had no prior knowledge about the DCA.

(Un)certainty regarding the DCA

Table 4 presents the frequency of patterns of emotional reactions and the average intensity of the different emotions as a function of the degree of uncertainty regarding the DCA. The results confirmed our fifth hypothesis for both mothers and fathers: uncertainty regarding the DCA was significantly associated with a pattern of high intensity emotional reactions at the disclosure.

In addition, when considering the intensity of the different emotions, it was found that mothers whose infants' DCA had some degree of uncertainty felt significantly more anger and sadness than did mothers whose infants' DCA had been clearly identified (see Table 4). Moreover, fathers whose infants' DCA had some degree of uncertainty felt significantly more shock than did fathers whose infants had a clearly identified DCA (see Table 4).

Parity

Our results did not confirm our sixth hypothesis. We found that the existence of previous positive reproductive experiences (previous healthy children) was not significantly associated with the patterns of emotional reactions for mothers ($\chi^2 = 0.06$, p = .809) or for fathers ($\chi^2 = 0.01$, p = .982). However, some differences in the intensity of the different emotions as a function of parity were found, only for mothers. Specifically, mothers who had other children felt significantly more hope (M = 82.7, SD = 25.5, Z = -1.89, p = .059) but less anger (M = 21.0, SD = 37.9, Z = -2.13, p = .033) than did primiparous mothers (hope: M = 69.5, SD = 31.9; anger: M = 32.9, SD = 38.8).

History of pregnancy loss

Table 5 presents the frequency of patterns of emotional reactions and the average intensity of the different emotions as a function of history of pregnancy loss.

As shown in Table 5, mothers who had a history of pregnancy loss presented a pattern of low-intensity negative emotional reactions at the disclosure of a DCA significantly more frequently, but no significant effect was found for fathers.

However, when considering the intensity of the different emotions, differences were found as a function of history of pregnancy loss for both mothers and fathers. Mothers with a history of pregnancy loss experienced significantly less despair and frustration than did

mothers without a history of pregnancy loss. Conversely, when there was a history of pregnancy loss in the couple, fathers experienced significantly more relief and significantly less hope than did fathers with no history of pregnancy loss.

Discussion

This study adds to the existing knowledge about parents' emotional reactions when they first learn of their infant's DCA. This topic has been investigated very little, despite its importance; initial reactions to the disclosure of a DCA may influence the way parents understand the information given and, consequently, the way they address it (Abramsky, Hall, Levitan, & Marteau, 2001; Aite, Zaccara, Trucchi et al., 2006).

First, our results showed that mothers and fathers had a similar emotional experience in response to a DCA and that intra-couple congruence was highly frequent. In addition to both members of the couple going through the same experience (the occurrence of a DCA in their infant), there are mutual influences within the couple (Cook & Kenny, 2005); that is, the reactions of one member of the couple influence the reactions of the other member and viceversa. These results confirm that both parents' experiences should be recognized, and that the paternal experience should not be neglected after a prenatal or postnatal DCA.

Second, the clinical variables (DCA characteristics and obstetric history) were found to influence the initial emotional reactions to the DCA for both mothers and fathers. Specifically, some clinical variables were associated with a significantly higher likelihood of parents presenting a pattern of high intensity negative emotional reactions at the disclosure of the DCA: uncertainty regarding their infant's DCA, for both mothers and fathers; having no prior knowledge about the DCA, for fathers; and having no history of pregnancy loss, for mothers. The remaining clinical variables (type and timing of the DCA and parity) were not predictive of the patterns of emotional reactions for either gender. However, differences in the intensity of specific emotions were found for all clinical variables.

[Insert_callout_2_about_here]

In fact, confirming our second hypothesis and in accordance with the existing research on this topic (Lalor et al., 2009; Mitchell, 2004), parents of infants diagnosed with different types of congenital anomalies presented mostly similar emotional reactions to the disclosure of the DCA. Overall, these results support a non-categorical approach to the understanding of the familial impact of the DCA, that is, an approach that seeks to consider the common impact of having a child with a medical condition (in this case, a congenital anomaly; Silver, Westbrook, & Stein, 1998).

Similarly, the timing of the DCA was not predictive of different patterns of emotional reactions for mothers or fathers, consistent with previous research (Nusbaum et al., 2008) and confirming our third hypothesis. However, differences in the intensity of some maternal emotions were found: mothers whose infants' DCA was disclosed during pregnancy felt more anger and sadness than did mothers whose infants' DCA was disclosed after birth. It is possible that mothers whose infants' DCA is disclosed during pregnancy may perceive that their body failed in its role of protecting the baby (Mander, 2005), and have difficulty in dealing with the lack of information until the infant's birth (Statham et al., 2000), intensifying their anger and sadness.

Moreover, our results regarding prior knowledge about the DCA confirmed our fourth hypothesis, for fathers only. Fathers who had no prior knowledge about the DCA may perceive it as more unexpected, because they were unaware of the condition and/or of the possibility that the condition could be diagnosed in the prenatal or postnatal period. They also may have no expectations regarding the future implications of the DCA and are confronted with complex information (Aite et al., 2004), which can contribute to an appraisal of the situation as more demanding and less controllable and, thus, may translate into a pattern of high-intensity negative emotional reactions at the disclosure of a DCA. However, a different

pattern was found for mothers. Our results showed that mothers with prior knowledge about the DCA felt significantly more guilt and frustration than did mothers without prior knowledge about the diagnosis. On the one hand, mothers with prior knowledge about the DCA may be more aware of its implications and prognosis, which may intensify their negative emotions. On the other hand, those mothers' feelings of guilt may be related with their perception of failure in protecting their infant (Mander, 2005) when they had prior knowledge about the DCA (e.g., its causes), even though they could not do anything to prevent the congenital anomaly (maternal self-blame; Danseco, 1997). However, this hypothesis should be further explored.

In addition, and confirming our fifth hypothesis, the perceived uncertainty regarding the DCA was significantly predictive of a pattern of high intensity negative emotional reactions for both mothers and fathers. Uncertainty regarding the condition contributes to an appraisal of the situation as being more undefined and unpredictable and, consequently, less controllable (Aite et al., 2009). This effect may prevent parents from clearly defining strategies to cope with the diagnosis (Lipinski, Lipinski, Biesecker, & Biesecker, 2006), and thus create expectations of worse outcomes, leading to high-intensity negative emotional reactions at the disclosure.

Finally, we investigated the role of obstetric history in the maternal and paternal emotional reactions to the disclosure of a DCA. We hypothesized that prior reproductive experiences help parents to develop expectations regarding the current reproductive experience. Regarding parity, our results did not confirm our sixth hypothesis. Having previous healthy children was not significantly associated with a pattern of high-intensity negative emotional reactions for either mothers or fathers. In fact, mothers with previous healthy children felt significantly more hope and less anger than did primiparous mothers; we

hypothesize that mothers with previous children may have a more positive perception about their future care of a child with a DCA. This hypothesis should be further explored.

In addition, our results showed that mothers with prior negative reproductive experiences (history of pregnancy loss) presented a pattern of low-intensity negative emotional reactions at the disclosure of a DCA more frequently, which is contrary to the results found by Aite, Zaccara, Nahom et al. (2006). Mothers with prior negative reproductive experiences may have developed more negative expectations regarding the current pregnancy outcomes (e.g., that something might be wrong with the infant) and consequently, may perceive the disclosure of a DCA as less unexpected than would mothers without a history of pregnancy loss, leading to less intense negative emotional reactions. Conversely, a different pattern of results was found for paternal emotional reactions to the disclosure of a DCA. Although a history of pregnancy loss was not significantly associated with a pattern of lowintensity negative emotional reactions for fathers, we found that fathers with prior negative reproductive experiences felt more relief at the disclosure than did fathers with no history of pregnancy loss. As fathers with pregnancy loss history may have developed negative expectations regarding the current pregnancy outcomes, they may feel some relief at the disclosure, because they appraise the current situation (the occurrence of a DCA) as not as bad as their prior situation (pregnancy loss). In addition, fathers with a history of pregnancy loss felt less hope than did fathers with no history of pregnancy loss; given their prior negative experience, they may have more difficulty in developing positive expectations regarding the DCA outcomes. These hypotheses should be further explored.

In conclusion, two main findings summarize our results concerning the influence of clinical variables in parents' emotional reactions. First, the clinical variables are important because they define the stressor event, that is, the occurrence of a DCA. Second, the clinical variables that most strongly influenced the parents' emotional reactions were those that define

the stressor event in terms of its level of unexpectedness (e.g., prior negative reproductive experiences, prior knowledge about the DCA) and its level of ambiguity/unpredictability (e.g., (un)certainty regarding the DCA). As mentioned by Boss (2002), depending on the characteristics of the stressor event, the parents will develop an appraisal of it as more or less threatening. When the DCA is more unexpected and less predictable, it may lead to a parental appraisal of the DCA as more threatening, less controllable, more demanding, and more difficult to cope with (Lipinski et al., 2006), which may translate into the parents' high-intensity negative emotional reactions when they first learn of their infant's DCA.

Additionally, the parental appraisal of the DCA may influence the resources that parents will activate to address it (Boss, 2002). Thus, the clinical variables are extremely important when considering the familial response to their infant's DCA and should be taken into account by health professionals.

Despite the exploratory nature of our study, the inclusion of both mothers and fathers and its quantitative approach are important methodological contributions to the field and allow for some interesting findings. However, this study has some limitations that should be acknowledged: 1) the reduced sample size, especially when assessing the effect of the type of congenital anomaly; 2) the retrospective assessment of emotional reactions, due to ethical considerations, although research highlights that parents can retrospectively describe their reactions at the disclosure in great detail (Drotar et al., 1975); and 3) the assessment of emotional reactions by a specific question responded to by means of visual analogue scales, which need further validation, instead of using an instrument measuring grief reactions, due to the absence, to our knowledge, of specific instruments focused on assessing the range of both negative and positive emotions (e.g., hope) that emerged from the literature review, and on the emotional experience, rather than its manifestations. Future studies should try to overcome these limitations and should further explore the relationship between clinical variables,

parental perceptions about the DCA, and family resources to address with the infant's DCA.

The replication of these results in other cultural contexts should also be explored.

[Insert_callout_3_about_here]

Finally, our results allow us to draw some clinical implications. First, clinical variables (DCA characteristics and obstetric history) may help health professionals to identify parents who are more likely to experience high intensity negative emotional reactions when the DCA is disclosed. Appropriate time and space to express their emotions should be provided to all parents after the disclosure. However, parents who present higher intensity emotional reactions should be the focus of particular attention; while negative reactions are normative, more intense responses may hinder the understanding and the decision-making processes associated with the diagnosis (Aite et al., 2004) and are related to subsequent adjustment difficulties (Fonseca et al., 2011a). Parents should also be encouraged to share their appraisal of the DCA (stressful situation) with each other and with health professionals. When a higher threat is perceived (e.g., the DCA is perceived as less controllable, more unexpected, and more demanding), some strategies should be used to help parents cope with the situation: a) assess parents' information needs and provide specific and clear information (e.g., written information, information from other sources, Lipinski et al., 2006); b) assess parents' expectations related to caretaking tasks and provide adequate support in the parents' development of specific caretaking skills that are perceived as demanding (e.g., feeding an infant with a oro-facial cleft); c) help parents be aware of the short-term implications of the DCA (e.g., treatment options); and d) develop strategies to cope with the intense emotional reactions, namely promote the balance between emotional expression and involvement in rewarding/distracting activities. All these strategies may help parents to restore the perception of control to the situation and to foster their self-efficacy when dealing with the demands imposed by the infant's DCA.

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Table 1
Sample Socio-Demographic and Clinical Characteristics

| Socio-demographic | Mothers ^a | Fathers ^b | |
|--------------------------------|----------------------|----------------------------|----------|
| characteristics | M (SD) | M (SD) | t |
| Age (years) | 31.22 (4.83) | 32.66 (4.99) | -1.54 |
| Educational level (years) | 14.27 (3.39) | 12.22 (3.36) | 3.14* |
| - | n (%) | n (%) | χ^2 |
| Marital status | | | |
| Married/Living together | 54 (90.0) | 47 (94.0) | 0.58 |
| Single/Divorced | 5 (10.0) | 3 (6.0) | |
| Professional status | | | |
| Employed | 50 (83.3) | 47 (94.0) | 2.98 |
| Unemployed | 10 (16.7) | 3 (6.0) | |
| Clinical variables - Obstetric | | Mothers ^a | |
| history | | n (%) | |
| Parity | | | |
| Primiparity | | 29 (48.3) | |
| Multiparity | | 31 (51.7) | |
| History of pregnancy loss | | | |
| Yes | | 11 (18.3) | |
| No | | 49 (81.7) | |
| Clinical characteristics – DCA | | Infants' data ^a | |
| characteristics | | n (%) | |
| Timing of DCA | | | |
| Prenatal | | 41 (68.3) | |

| Postnatal | | 19 (31.7) | |
|---------------------------------|----------------------|----------------------|----------|
| Type of congenital anomaly | | | |
| Congenital heart disease | | 17 (28.3) | |
| Nervous system anomalies | | 9 (15.0) | |
| Digestive system anomalies | | 6 (10.0) | |
| Urinary system anomalies | | 16 (26.7) | |
| Oro-facial clefs | | 7 (11.7) | |
| Limb anomalies | | 5 (8.3) | |
| (Un)certainty regarding the DCA | | | |
| Certainty | | 19 (31.7) | |
| Uncertainty | | 41 (68.3) | |
| Clinical characteristics – DCA | Mothers ^a | Fathers ^b | |
| characteristics | n (%) | n (%) | χ^2 |
| Prior knowledge of the DCA | | | |
| Yes | 25 (41.7) | 19 (38.0) | 0.15 |
| No | 35 (58.3) | 31 (62.0) | |

n = 60. n = 50. p < .01.

Table 2 Gender Differences on Cluster Membership and Average Intensity of the Parents' Emotional Reactions at the Disclosure of a DCA

| | Mothers ^a | Fathers ^b | |
|--------------------|----------------------|----------------------|----------|
| Cluster membership | n (%) | n (%) | χ^2 |
| High-intensity | 32 (57.1) | 24 (42.9) | 0.31 |
| Low-intensity | 28 (51.9) | 26 (48.1) | |
| Emotions | M (SD) | M (SD) | F |
| Guilt | 31.52 (36.99) | 16.16 (30.24) | 6.83* |
| Anger | 24.26 (36.26) | 24.20 (38.08) | 0.00 |
| Anxiety | 77.12 (31.35) | 73.84 (32.16) | 0.94 |
| Sadness | 81.40 (30.47) | 77.34 (30.10) | 0.58 |
| Shock | 68.22 (37.33) | 58.58 (39.94) | 2.85 |
| Despair | 49.12 (39.64) | 39.42 (39.25) | 2.79 |
| Shame | 8.68 (21.45) | 3.98 (12.91) | 2.09 |
| Frustration | 38.04 (40.39) | 34.80 (48.82) | 0.33 |
| Relief | 7.78 (23.39) | 10.26 (24.25) | 0.58 |
| Норе | 74.58 (29.73) | 79.22 (27.87) | 1.33 |

n = 60. n = 50. p < .05.

Table 3 Variability of Maternal and Paternal Emotional Reactions as a Function of Prior Knowledge about the DCA

| | Mothers ^a | | | Fath | ners ^b | |
|----------------|----------------------|-------------|--------------------|-------------|-------------------|--------------------------|
| | No prior | Prior | | No prior | Prior | _ |
| | knowledge | knowledge | | knowledge | knowledge | |
| Cluster | n (%) | n (%) | χ^2 | n (%) | n (%) | χ^2 |
| High-intensity | 17 (53.1) | 15 (46.9) | 0.77 | 18 (75.0) | 6 (25.0) | 3.31 [†] |
| Low-intensity | 18 (64.3) | 10 (35.7) | | 13 (50) | 13 (50) | |
| Emotions | M (SD) | M(SD) | Z | M (SD) | M(SD) | Z |
| Guilt | 25.1 (34.6) | 43.6 (41.5) | -2.18* | 13.5 (27.8) | 20.6 (34.2) | -0.69 |
| Anger | 23.6 (37.9) | 31.2 (39.7) | -1.08 | 26.1 (38.8) | 23.5 (37.7) | -0.02 |
| Sadness | 86.4 (25.6) | 77.8 (32.9) | -0.57 | 83.4 (24.8) | 67.1 (35.6) | $\text{-}1.84^{\dagger}$ |
| Anxiety | 81.6 (32.7) | 77.1 (25.8) | -1.56 | 76.8 (31.6) | 69.1 (33.3) | -1.35 |
| Shock | 67.2 (36.6) | 71.4 (35.4) | -0.40 | 71.5 (33.8) | 37.6 (41.1) | -2.79** |
| Despair | 45.2 (39.2) | 57.1 (41.5) | -1.33 | 29.3 (36.3) | 39.4 (39.2) | -1.58 |
| Shame | 8.5 (24.2) | 13.5 (28.4) | -1.81 [†] | 4.1 (13.8) | 3.8 (11.7) | -0.42 |
| Frustration | 28.3 (38.3) | 56.1 (41.9) | -2.75** | 41.4 (44.0) | 24.1 (33.3) | -1.10 |
| Relief | 10.3 (27.6) | 9.6 (26.2) | -0.76 | 13.9 (28.9) | 4.3 (12.2) | -0.82 |
| Норе | 78.4 (30.2) | 73.4 (28.3) | -0.74 | 84.2 (19.9) | 71.1 (36.6) | -1.13 |

a = 60. b = 50. p < .05. p < .01.

Table 4 Variability of Maternal and Paternal Emotional Reactions as a Function of (Un)certainty Regarding the DCA

| | Mothers ^a | | | Fath | ners ^b | |
|----------------|----------------------|-------------|------------------|-------------|-------------------|----------|
| | Uncertainty | Certainty | _ | Uncertainty | Certainty | _ |
| Cluster | n (%) | n (%) | χ^2 | n (%) | n (%) | χ^2 |
| High-intensity | 25 (78.1) | 7 (21.9) | 3.04^{\dagger} | 19 (79.2) | 5 (20.8) | 4.61* |
| Low-intensity | 16 (57.1) | 12 (42.9) | | 13 (50.0) | 13 (50.0) | |
| Emotions | M(SD) | M (SD) | Z | M(SD) | M(SD) | Z |
| Guilt | 39.4 (41.4) | 18.7 (26.6) | -1.24 | 15.6 (28.6) | 17.2 (33.9) | -0.30 |
| Anger | 32.5 (40.1) | 14.4 (32.3) | -2.00* | 29.8 (38.4) | 16.8 (37.0) | -2.03* |
| Sadness | 88.9 (22.1) | 69.6 (37.2) | -1.93* | 81.6 (25.6) | 69.8 (36.4) | -0.85 |
| Anxiety | 89.4 (27.8) | 72.0 (33.3) | -1.08 | 73.4 (33.5) | 74.7 (37.2) | -0.05 |
| Shock | 73.0 (34.4) | 60.4 (38.3) | -1.01 | 68.1 (38.8) | 41.7 (37.2) | -2.37* |
| Despair | 55.4 (39.1) | 38.9 (41.7) | -1.23 | 44.0 (39.8) | 31.3 (37.9) | -1.24 |
| Shame | 14.2 (30.4) | 2.8 (7.6) | -1.36 | 5.5 (15.8) | 1.2 (3.6) | -0.91 |
| Frustration | 45.1 (43.1) | 28.7 (37.6) | -1.33 | 38.8 (42.9) | 27.6 (36.9) | -1.05 |
| Relief | 13.7 (31.6) | 2.2 (6.3) | -1.23 | 12.7 (27.1) | 5.9 (18.0) | -1.12 |
| Норе | 75.7 (28.7) | 77.7 (31.3) | -0.56 | 81.3 (25.1) | 75.6 (32.7) | -0.39 |

a n = 60. b n = 50. b p < .10. * p < .05.

Table 5 Variability of Maternal and Paternal Emotional Reactions as a Function of History of Pregnancy Loss (Presence vs. Absence)

| | Mothers ^a | | | Fathers ^b | | |
|----------------|----------------------|-------------|------------------|----------------------|-------------|----------|
| | History of | No history | | History of | No history | |
| | pregnancy | of | | pregnancy | of | |
| | loss | pregnancy | | loss | pregnancy | |
| | | loss | | | loss | |
| Cluster | n (%) | n (%) | χ^2 | n (%) | n (%) | χ^2 |
| High-intensity | 3 (9.4) | 29 (90.6) | 3.68^{\dagger} | 6 (25.0) | 18 (75.0) | 1.53 |
| Low-intensity | 8 (28.6) | 20 (71.4) | | 3 (11.5) | 23 (88.5) | |
| Emotions | M (SD) | M (SD) | Z | M (SD) | M (SD) | Z |
| Guilt | 25.1 (36.0) | 34.6 (39.0) | -0.68 | 17.3 (33.7) | 15.9 (29.9) | -1.45 |
| Anger | 14.0 (32.2) | 29.7 (39.5) | -1.61 | 27.9 (41.6) | 23.4 (37.8) | -0.21 |
| Sadness | 72.9 (37.4) | 85.0 (26.6) | -0.48 | 82.9 (23.8) | 76.1 (31.4) | -0.08 |
| Anxiety | 75.3 (35.6) | 80.8 (28.8) | -0.07 | 81.8 (21.2) | 72.1 (34.1) | -0.47 |
| Shock | 53.6 (44.6) | 72.5 (33.2) | -1.08 | 66.1 (40.5) | 56.9 (40.1) | -0.15 |
| Despair | 24.7 (36.0) | 55.9 (39.3) | -2.34* | 45.3 (33.1) | 38.1 (40.7) | -0.79 |
| Shame | 10.6 (29.9) | 10.6 (25.3) | -0.01 | 7.0 (16.5) | 3.3 (12.1) | -1.90 |
| Frustration | 16.1 (31.7) | 45.2 (42.2) | -2.12* | 41.2 (36.5) | 33.4 (42.0) | -0.24 |
| Relief | 12.9 (30.0) | 9.4 (26.3) | -0.97 | 19.2 (23.9) | 8.3 (24.2) | -1.96* |
| Hope | 77.2 (41.0) | 76.1 (26.6) | -1.04 | 55.7 (30.5) | 84.4 (24.8) | -2.00* |

a n = 60. b n = 50. b p < .10. p < .05.