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Parental psychological distress and quality of life after a pre- or postnatal diagnosis of congenital anomaly: A controlled comparison study with parents of healthy babies

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Abstract

Background: Parental early adjustment to a pre- or postnatal diagnosis of congenital anomaly has been studied mainly within a pathological and deterministic perspective, giving us an inadequate view of the impact of the diagnosis.

Objectives: Adopting a comprehensive approach on parental adjustment, we aimed to characterise the impact of the diagnosis on psychological distress and quality of life, in the early post-diagnosis stage. The effects of gender and the timing of the diagnosis were also examined.

Methods: In this cross-section study, 42 couples with healthy babies and 42 couples whose babies were pre- or postnatally diagnosed with a congenital anomaly responded to the Brief Symptom Inventory-18 and to the World Health Organization Quality of Life-Bref instrument.

Results: In the early post-diagnosis stage, parents whose babies were diagnosed with a congenital anomaly presented higher levels of psychological distress than the parents of healthy babies ($F_{2,79} = 6.23, p = .003$), although they displayed similar levels of quality of life ($F_{4,78} = 0.62, p = .647$). Mothers reported more adjustment difficulties than fathers in both groups. Receiving the diagnosis in the prenatal period was associated with higher maternal psychological quality of life ($Z = -2.00, p = .045$).

Conclusion: The occurrence of a diagnosis of congenital anomaly during the transition to parenthood adds to an accumulation of stress-inducing events and manifests itself in psychopathological symptoms. Maintaining a positive evaluation of well-being may be understood as a parental resource to deal with the diagnosis. The importance of adopting a comprehensive perspective on parental adjustment is highlighted.

Introduction

The disclosure of a pre- or postnatal diagnosis of a congenital anomaly (DCA) suddenly and unexpectedly disrupts parental expectations of a healthy baby (1). Parents must cope with the dual challenge of the transition to parenthood and of the pre- or postnatal DCA, with its associated medical, financial, social, and emotional demands (2-4). With most studies focusing on long-term familial consequences of a DCA, little is known about parental adjustment during the early post-diagnosis stage (3, 5), especially when we consider other dimensions of adjustment besides psychological distress, such as quality of life (QoL). This study aimed to characterise the maternal and paternal psychological distress and QoL in the early post-diagnosis stage after a pre- or postnatal DCA in comparison with a group of parents of healthy babies in the same developmental period.

Psychological distress

As a deterministic and pathological perspective on the consequences to the family of the birth of a disabled child prevailed for several decades (6), psychological distress has predominantly been used as the indicator of parental adjustment to their child's DCA. Parents of babies with a pre- or postnatally identified DCA presented higher levels of anxiety (5, 7-9) and depression (8, 10, 11) after the diagnosis, in

comparison both with parents of healthy babies in the same developmental period and with the general population.

Increased levels of psychological distress were found in parents of babies with a DCA, whether it was pre- or postnatally identified, and research showed that, immediately after the diagnosis, there were no differences in psychological distress as a function of the timing of diagnosis (pre- or postnatal) (12). However, parents of babies with a prenatal diagnosis presented higher levels of psychological distress six weeks after the birth of the baby (13) and six months after the diagnosis (12) when compared with parents with a postnatally identified DCA. Brosig et al. (12) suggested that prenatal diagnosis may constitute a long-lasting psychological stressor for parents given the increased latency period between diagnosis and treatment availability. Another study showed a different pattern according to gender (14). During the period of the newborns' hospitalisation due to corrective surgery for congenital heart disease, fathers whose babies were prenatally diagnosed reported less anxiety when compared to fathers whose babies were diagnosed in the postnatal period, while both groups of mothers reported similar levels of anxiety.

Additionally, while most studies reported that mothers presented higher levels of psychological distress than fathers after a pre- or postnatal DCA (e.g., 15, 16), which was also found during the transition to parenthood in low-risk pregnancies (17, 18), one study found no gender differences (12). Moreover, other studies showed that existing gender differences with respect to psychological distress immediately after the DCA tended to disappear in subsequent evaluations at six weeks (13) and three months after the birth (11), suggesting some similarity between maternal and paternal experiences. Despite the contribution of these results to understanding parents' experience after a DCA and their specificities as a function of timing of diagnosis and gender, some

authors have underlined the need for a broader perspective of parents' adjustment to their child's diagnosis covering other important dimensions of well-being, such as QoL (19). This comprehensive approach to parental adjustment allows for an understanding of the broader impact of a DCA and, consequently, a clearer definition of health professionals' intervention goals and strategies.

Quality of life

Quality of life, as defined by the World Health Organization (20), encompasses an individual's perception of their own physical, psychological, social, and environmental well-being, taking into account their culture and value systems, as well as their goals and expectations. QoL has been increasingly used as a health status indicator in medical and public health research (21). The measure has informative value when assessing the adjustment of parents whose children have a DCA (19).

Studies focusing on parental QoL in the post-diagnosis stage are scarce. One exception is the study by Mazer et al. (3), which found that six weeks after birth, both mothers and fathers of babies with a DCA presented a lower QoL score on the mental component scale of the Medical Outcomes Study Short Form-36 when compared with the normative group. Mothers displayed a lower QoL score than fathers, especially in the physical component scale (3). However, in this study, the normative values of the general population were used as a reference, so the possibility remains that these differences were due to the experiences of pregnancy and parenting (a decline in QoL for mothers and fathers was found to be common, even in an uneventful pregnancy; 22, 23). Moreover, to our knowledge, no studies have assessed QoL after a prenatal DCA or the QoL variability as a function of the timing of diagnosis.

Additionally, other studies have shown that parents of children with congenital anomalies or disabilities reported a lower QoL, when compared with normative data, parents of healthy children, or parents of children with minor illnesses (e.g., respiratory tract infection, fever) (24-27). However, these studies comprised parents of children in different developmental phases, with different demands, and with a wide range of ages (e.g., a study included children from one month to 16 years, 27). Therefore, the results found cannot be generalised to the early post-diagnosis stage after a pre- or postnatal DCA. Although not specifically assessing QoL, a recent study found no differences in life satisfaction between mothers of babies with a prenatal diagnosis of congenital heart disease and mothers of healthy babies, either during pregnancy (30th gestation week) or at six months postpartum (28). According to the authors, satisfaction with life may be understood as a more comprehensive evaluation of the individual's life, including aspects other than the provision of care for a child with a DCA. Conversely, it was hypothesised that, given the diagnosis, mothers may have hope for the future and use coping strategies to remain in a positive state, suggesting that life satisfaction may be conceptualised as a personal resource in the face of adversity.

The scarcity of studies regarding QoL and the inconsistent results of the existing ones demonstrated that the impact of a pre- or postnatal DCA in other dimensions of parental well-being besides psychological distress (namely QoL) is yet to be determined, which may contribute to a deterministic and pathological perspective that, in turn, influences the practice of health professionals and researchers.

Aims and Hypotheses

In this study, we adopted a comprehensive approach to parental adjustment after a DCA. In addition to considering both maternal and paternal experiences, parental

adjustment was operationalised both in terms of psychological distress and QoL. We aimed 1) to examine parental adjustment after a pre- or postnatal DCA, in comparison with a group of parents of healthy babies (clinical vs. comparison group), 2) to investigate gender differences on parental adjustment in both groups, and 3) to examine the effect of the timing of diagnosis (pre- vs. postnatal) on adjustment of parents whose babies were diagnosed with a DCA.

Based on the literature review, our first hypothesis was that parents of babies with a pre- or postnatal DCA would present higher levels of psychological distress than the comparison group. Our second hypothesis was that women would report higher levels of psychological distress and lower levels of QoL than men, independently of the group. Given the absence of specific research on this topic, no hypotheses were put forth regarding the impact of a DCA in parental QoL, the interaction effects of gender and group, and the effects of the timing of diagnosis (pre- vs. postnatal) in parental adjustment in the clinical group.

Method

Procedure

This study was approved by the Ethics Committees of two Portuguese urban referral hospitals (Hospitais da Universidade de Coimbra and Centro Hospitalar de Coimbra). Inclusion criteria for the clinical group (parents of babies with a DCA) were: having a baby with a pre- or postnatally identified DCA, without the occurrence of perinatal death. A group of parents of healthy babies (babies without pre- or postnatally identified DCAs or other medical problems) similar to the parents of the clinical group regarding sociodemographic and clinical characteristics was constituted for comparison purposes (comparison group). For both groups, being 18 years or older and having a

level of literacy (education level \geq 6th grade) that allowed the comprehension of the assessment protocol was required.

The sample collection occurred between September 2009 and April 2011. For the clinical group, approximately one month after the disclosure of a DCA, all parents (consecutive sampling) were informed by the medical team about this investigation at the end of a medical appointment, and they were asked for their authorisation to be contacted by the researchers. Participants in the comparison group were approached by the researchers prior to their medical appointment (either during pregnancy or one month after the birth in a similar proportion to the assessment timing, pre- or postnatal, in the clinical group; consecutive sampling). We presented the research goals to all contacted parents and an informed consent was signed by those who decided to participate. Participants were given the questionnaires, and were told to return them to the researchers at the following medical appointment.

A total of 169 couples (69 from the clinical group) were contacted, of which 34 (18 from the clinical group) refused to participate or did not return the questionnaires (participation rate = 79.9%). We excluded eight couples in the clinical group because the questionnaires were filled out only by the women. In the comparison group, we selected 42 couples with sociodemographic and clinical characteristics similar to the clinical group (with the exception of maternal age - as this is a risk factor for congenital anomalies, we believe that it is a distinctive feature of the clinical group, that should be highlighted).

Measures

Psychological distress was evaluated with the Portuguese version of the Brief Symptom Inventory – BSI-18 (29), a 5-point Likert scale (from 0 = *Not at all* to 4 =

Extremely), which is comprised of three dimensions (Anxiety, Depression, and Somatization). Higher values indicate the presence of more intense psychopathological symptoms. According to the study goals, only the Anxiety and Depression dimensions were used. In our sample, Cronbach's alphas for Anxiety were .89 (clinical group) and .79 (comparison group) and for Depression were .87 (clinical group) and .84 (comparison group).

Quality of life was assessed with the Portuguese version of the World Health Organization Quality of Life brief instrument - WHOQOL-BREF (30). By comparison to the original version of the instrument (WHOQOL-100), the brief version also revealed adequacy in assessing the construct of QoL (31), with the advantage of being easier and faster to fill by the participants. The WHOQOL-BREF questionnaire consists of 26 items (answered on a 5-point Likert scale) organised into a facet of *overall QoL* (general perception of QoL and health) and four specific domains, each one assessing the following dimensions: *physical* (pain and discomfort, energy and fatigue, sleep and rest, dependence on medication, mobility, activities of daily living, and working capacity; in our sample, Cronbach's alphas = .74 for the clinical group and .83 for the comparison group), *psychological* (positive and negative feelings, self-esteem, thinking learning, memory and concentration, body image, and spirituality, religion and personal beliefs; Cronbach's alphas = .79 both for clinical and comparison groups), *social relationships* (personal relations, sexual relations, social support; Cronbach's alphas = .67 for the clinical group and .75 for the comparison group), and *environment* (financial resources, information and skills, recreation and leisure, home environment, access to health and social care, physical safety and security, physical environment and transport; Cronbach's alphas = .77 for the clinical group and .81 for the comparison group).

Higher scores indicate better QoL. Given its low Cronbach's alpha ($< .60$) in our sample, the *overall facet* of QoL was not used.

We also collected sociodemographic (gender, age, marital status, educational level, and professional status) and clinical information (obstetric history – parity, pregnancy loss, infertility, and other complications; current pregnancy data – gestational age and pregnancy complications; the baby's data – age and health problems; and DCA - type of congenital anomaly, timing of diagnosis – pre- vs. postnatal, hospitalization in the NICU, need of surgery).

Data Analyses

Analyses were conducted with IBM SPSS, version 19.0. We performed the data analyses using the couple as a unit to take into account the interdependence of the couple's observations. The database was restructured to consider each couple as the subject of the analysis and each partner's score as a different variable.

We used descriptive statistics for the demographic and clinical characterisation of the sample and to describe parental adjustment (psychological distress and QoL). Chi-squared tests and *t*-tests were used to compare groups based on sociodemographic characteristics. The effects of gender and group in parental adjustment (psychological distress and QoL) were assessed with repeated-measures MANOVAs with group (clinical, comparison) as the between-subjects factor and gender (female, male) as the within-subjects factor. ANOVAs were used when the multivariate effect was significant. We examined the association between maternal and paternal adjustment with Pearson's correlations. The effect of the timing of diagnosis in parental adjustment was evaluated with non-parametric tests (Mann-Whitney U) because necessary assumptions for parametric tests were not met. Because of the interdependence of the couple's observations, we presented the results separately for mothers and fathers.

Post hoc power calculations made for all parametric statistical analyses performed with a significance level of .05 and power $\geq .80$ indicated that medium to large effects could be detected (32). As a result, significance was defined as $p < .05$ but marginally significant results ($p \leq .10$) were also reported. Effect-size measures are presented for all comparison analyses (small: $\eta^2 \geq .01$, $r \geq .1$, $d \geq .20$, medium: $\eta^2 \geq .06$, $r \geq .3$, $d \geq .50$, large: $\eta^2 \geq .14$, $r \geq .5$, $d \geq .80$) (33).

Results

Sociodemographic and clinical characteristics of the sample

The final sample was comprised of 84 couples (42 from the clinical group and 42 from the comparison group). Sociodemographic and clinical data are presented in Table 1. We found no significant differences between groups with regard to sociodemographic and clinical characteristics, except for maternal age ($t_{82} = 2.22$, $p = .029$; mothers of the clinical group were significantly older than the mothers of the comparison group). Regarding the characteristics of the DCA, the majority of diagnoses occurred during pregnancy, but none of the pregnancies were terminated. Only in 10.3% ($n = 4$) of cases there was a diagnosis of multiple congenital anomalies.

(Table_1_about_here)

Impact of a DCA in parental adjustment: clinical vs. comparison group

Table 2 presents descriptive statistics regarding parental adjustment according to group and gender, and also univariate analyses regarding group and gender effects in parental adjustment. Associations between maternal and paternal adjustment in both groups are also presented.

Regarding psychological distress, we found a significant multivariate group effect (Pillai's Trace = .136, $F_{2,79} = 6.23$, $p = .003$, $\eta^2 = .136$): the univariate analyses revealed significant differences in anxiety and in depression, with parents of the clinical group presenting higher scores. Conversely, we found no significant multivariate group effect on QoL (Pillai's Trace = .031, $F_{4,78} = 0.62$, $p = .647$, $\eta^2 = .031$) (see Table 2).

Gender differences

Our results showed a multivariate effect of gender in psychological distress (Pillai's Trace = .159, $F_{2,79} = 7.45$, $p = .001$, $\eta^2 = .159$): women presented significantly higher levels of anxiety (Mothers: $M = 5.94$, $SD = 4.41$ vs. Fathers: $M = 4.57$, $SD = 4.45$) and depression (Mothers: $M = 4.72$, $SD = 4.40$ vs. Fathers: $M = 3.10$, $SD = 3.74$). However, we found no interaction effects between gender and group in psychological distress (Pillai's Trace = .002, $F_{2,79} = 0.074$, $p = .929$, $\eta^2 = .002$).

Similarly, our results showed gender differences in QoL (Pillai's Trace = .372, $F_{4,78} = 11.57$, $p < .001$, $\eta^2 = .372$). The univariate analyses indicated that differences occurred in the physical (Mothers: $M = 69.04$, $SD = 13.72$ vs. Fathers: $M = 79.13$, $SD = 11.66$) and psychological domains (Mothers: $M = 73.48$, $SD = 12.87$ vs. Fathers: $M = 79.80$, $SD = 12.76$), with mothers presenting lower QoL than fathers. Also we found a significant interaction effect between gender and group in QoL (Pillai's Trace = .118, $F_{4,78} = 2.62$, $p = .041$, $\eta^2 = .118$), specifically in the physical ($F = 5.15$, $p = .026$) and environmental ($F = 7.34$, $p = .008$) domains. The results of post-hoc analyses revealed that, with regard to the physical domain, gender differences were observed in both groups (clinical group: $t_{40} = -2.52$, $p = .016$, $d = .394$; comparison group: $t_{40} = -5.60$, $p < .001$, $d = .884$), while regarding the environmental domain, gender differences only

occurred in the clinical group (clinical group: $t_{40} = 2.94, p = .005, d = .447$; comparison group: $t_{40} = -1.07, p = .292, d = .165$).

In the clinical group, our results showed significant medium to large associations between maternal and paternal adjustment, with the exception of physical QoL. However, in the comparison group, significant associations between maternal and paternal scores were only found in anxiety, and in social relationships and environmental QoL (see table 2).

(Table_2_about_here)

Timing of diagnosis (pre vs. postnatal)

We found no differences in psychological distress as a function of the timing of diagnosis for either gender. Mothers whose babies were diagnosed in the prenatal period ($M = 75.82, SD = 11.75$) presented higher psychological QoL than mothers whose babies were diagnosed after birth ($M = 66.67, SD = 12.91; Z = -2.00, p = .045, r = .031$), but no differences were found in the other QoL domains. The timing of the diagnosis did not have a significant effect on paternal QoL.

Discussion

The main finding of this study is that, in the early post-diagnosis stage, parents whose babies were diagnosed with a congenital anomaly presented higher levels of psychological distress than parents of healthy babies, while their levels of QoL were similar. The occurrence of the DCA appears to have, in the early post-diagnosis stage, a greater impact on particularly emotional and overt manifestations (anxiety and

depression) rather than on dimensions that reflect a global evaluation of individual well-being.

Impact of a DCA in parental adjustment

Results concerning psychological distress were consistent with findings of other studies (e.g., 8, 9), confirming our first hypothesis. These results seem to support the idea that the occurrence of a DCA is a stress-inducing event for the family, beyond the transition to parenthood itself, which is also a distressing experience (18, 34). Parents of babies with a DCA have to deal simultaneously with the stressors associated with the diagnosis and stressors associated with the transition to parenthood, which may result in a greater challenge to the parental adaptation process and is likely to manifest itself in higher levels of psychological distress. These results are also consistent with stress and family crisis theories (35, 36), which argue that the accumulation of stress-inducing events is a potential factor for crisis in the family system. Additionally, given the unexpectedness (37) and significance of the DCA (the loss of a healthy baby) (38) to parents, anxious and depressive manifestations can be seen as an expected and normative expression of the parental experience in the early post-diagnosis stage.

We found no differences in parental QoL as a function of group. These results contrast with the lower QoL found in parents of babies with a DCA in the early post-diagnostic stage (3) and with findings regarding QoL in parents of children with congenital anomalies in different developmental phases (24, 39). Differences found in these studies may be due to the use of normative data, rather than parents of healthy babies, as comparison groups, and/or to the use of samples including children in different developmental phases. On the other hand, our results were similar to the ones found by Dale et al. (28) regarding life satisfaction. Parent's evaluation of their QoL reflects their perception of well-being in several dimensions (e.g., physical,

psychological, and social) taking into account the larger context (39); therefore, assessing the individual perception of QoL involves assessing a broader dimension of individual adjustment, which is not restricted to psychological distress (19, 21). A possible explanation for our results is that, at least in the early post-diagnosis stage, the occurrence of a DCA may not have a significant impact on QoL, understood as a general evaluation of several life domains (e.g., financial, social), although it has a significant impact on more specific dimensions of parental adjustment, that is, emotional adjustment. Additionally, as pointed out by Dale et al. (28), these results may reflect an active effort of parents to maintain a positive assessment of their life and well-being in the early post-diagnosis stage, which may act as a resource for dealing with the diagnosis. These hypotheses should be addressed in future studies.

Gender differences

In our study, mothers experienced more adjustment difficulties than fathers in both groups, confirming our second hypothesis. Gender differences may be explained by the larger set of changes experienced by mothers during the transition to parenthood (e.g., physical, emotional changes), along with their main role as caregivers (34). There were also some group specificities, namely the existence of significant differences between mothers and fathers in environmental QoL, only in the clinical group: fathers perceived lower QoL than mothers. These findings may be related to the fact that fathers were more focused on dealing with the financial and other practical demands associated with the diagnosis, when compared to mothers (14). Additionally, after a DCA, mothers may tend to express their distress more, because they have to deal with specific issues which they may perceive as a loss of their parental role (e.g., greater monitoring of the pregnancy, which could prevent them from making decisions about childbirth; the baby's first perinatal care provided in a NICU, when mothers were

usually the primary caregiver after the baby's birth) (38, 40), while fathers tend to contain their emotions, by assuming a supportive role of their partners (41).

Despite the differences found, our results also highlighted a shared experience within the couple (as expressed by the positive associations between maternal and paternal adjustment) in the face of stress-inducing events, such as the transition to parenthood and the occurrence of a pre- or postnatal DCA. Further studies should examine the role that (dis)similar experiences may have on the individual adjustment of each partner.

Timing of diagnosis

Our results showed no differences on psychological distress as a function of the timing of the diagnosis. These results were similar to those of Brosig et al. (12) and suggest that, although a prenatal diagnosis was found to constitute a risk factor for subsequent maladjustment (13), this is not the case in the early post-diagnosis stage.

To our knowledge, this was the first study to assess the relationship between timing of the diagnosis and maternal and paternal QoL, and our results were innovative, despite their exploratory nature. Psychological QoL was higher in mothers whose babies were diagnosed in the prenatal period. These women, contrary to the mothers of babies with postnatal diagnoses, are often confronted with uncertainty and a waiting period until the birth of the baby, when more information about the prognosis and treatment options is available (42). On the one hand, it is possible that these mothers seek to retain a positive state of mind, as a resource to deal with this waiting and uncertainty period (28). On the other hand, a possible interpretation is that these results may be related with difficulty accepting the reality of the diagnosis, i.e., the expectation that the diagnosis will not be confirmed after the birth of the baby (43). However, we

consider that this interpretation is unlikely, given the absence of differences found in psychological distress, which underline the impact of the DCA. The absence of differences in paternal QoL may be due to the fact that, regardless of the timing of diagnosis, fathers tend to focus on dealing with the practical requirements – rather than with the emotional issues – associated with both the diagnosis and the transition to parenthood (14) and on trying to assume a protective role of their partners (41). Future research is needed to clarify the effect of the timing of the diagnosis on parental QoL.

Strengths and limitations of the study

The main contribution of this study was the adoption of a comprehensive approach to parental adjustment, including not only psychological distress but also other dimensions of well-being, namely physical and psychological QoL. This approach allowed us to draw a more complete profile of the initial impact of the DCA in parental adjustment, highlighting the importance of adopting, in research and clinical practice, a non-deterministic and non-pathological perspective, and underscoring the relevance of QoL as an indicator of adjustment with informative value in health contexts. Additionally, methodological options regarding sampling (namely, the inclusion of a comparison group, with parents of both groups being in the same phase of the life cycle) and assessment time (all parents of the clinical group were evaluated one month after the DCA), made it possible to assess the specific impact of the diagnosis on QoL, something that had not been done previously. The use of couples, rather than just mothers, was another strength of our study, because it took into account the experience of both members of the couple, and provided insight into couple's (di)similarities on adjustment to a pre- or postnatal DCA, which is an individual, but also a familiar experience.

However, there are also some limitations to the study. First, the power analysis (*a posteriori*) showed that small effects could not be detected given the sample size (32). Another limitation concerns the inclusion of different types of congenital anomalies (with different prognoses and treatment options) in the sample. Although we believe it is important to consider the specific impact of different congenital anomalies (e.g., congenital heart disease), we opted for a non-categorical approach, which advocates more similarities than differences in the parental psychosocial implications of chronic health conditions (44). Therefore, we find it is essential to understand the shared parental experience of receiving a pre- or postnatal DCA because early healthcare normally takes place in maternity departments, where professionals (obstetricians, neonatologists, midwives) encounter different types of DCA.

Conclusions and practical implications

Despite our detachment from the deterministic perspective, health professionals must recognise that the occurrence of a DCA during the transition to parenthood adds to an accumulation of stress-inducing events, which may result in an increased risk of developing psychopathological symptoms in the early post-diagnosis stage, although these symptoms may be understood as the result of a normative process of individual adjustment to the stress-inducing events (35). Specifically, we highlight the essential role of a comprehensive assessment of parental adjustment, in order to characterise the parents' response to a DCA and to target for specialised counselling those who score worse on indices of adjustment.

In addition to more specialised interventions, parents of babies with a DCA can benefit from brief counselling, addressing some of the parental difficulties in adapting to both the transition to parenthood and the occurrence of a DCA, using intervention strategies such as psychoeducation (about the physical, psychological and social

changes during the transition to parenthood and the main challenges of dealing with the diagnosis), decision-making and problem-solving training, and emotional expression strategies (giving parents the opportunity to express emotions and perceptions about the DCA). Moreover, as the dissimilarity of intracouple adjustment to stress-inducing events may itself be a source of stress (45), this issue should also be addressed in the context of brief counselling or more specialised interventions.

Finally, although they were exploratory, the QoL results suggest the possibility that a positive evaluation of well-being may be a resource in times of adversity; therefore, dimensions of poorer well-being should be identified for each individual and fostered in health care interventions (e.g., in the physical domain, the introduction of sleep hygiene strategies; in the social relationships domain, the activation of social support networks).

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Legends

Table 1. Sociodemographic and clinical characteristics of the sample ($N = 84$ couples)

Table 2. Maternal and paternal psychological distress and QoL: Descriptive statistics, correlations, group and gender effects

Table 1. Sociodemographic and clinical characteristics of the sample ($N = 84$ couples)

	Clinical group ($n = 42$ couples)		Comparison group ($n = 42$ couples)	
	Mothers	Fathers	Mothers	Fathers
Demographic characteristics				
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>
<i>Age</i>	31.2 (4.5)	32.0 (4.4)	29.2 (2.7)	31.5 (3.9)
<i>Education years</i>	14.9 (3.2)	12.6 (3.4)	14.0 (2.7)	12.0 (4.0)
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
Professional status				
Employed	38 (90.5)	40 (95.2)	32 (76.2)	37 (88.1)
Unemployed	4 (9.5)	2 (4.8)	10 (23.8)	5 (11.9)
Clinical characteristics				
	<i>n (%)</i>		<i>n (%)</i>	
Parity				
Primiparous	28 (66.7)		28 (66.7)	
Multiparous	14 (33.3)		14 (33.3)	
Complications in current pregnancy (e.g., diabetes, hypertension)				
	9 (22)		7 (16.7)	
Obstetric history				

Pregnancy loss	6 (14.3)	6 (14.3)
Infertility problems	5 (11.9)	3 (7.1)
<i>Timing of DCA</i>		
Prenatal diagnosis	31 (73.8)	
	[Gestational age: $M = 23.7$ weeks, $SD = 5.6$]	
Postnatal diagnosis	11 (26.2)	
<i>Type of DCA</i>		
Urinary system anomalies	13 (31.0)	
Congenital heart disease	10 (23.8)	
Visible anomalies	9 (10.1)	
Nervous system anomalies	5 (11.9)	
Digestive system anomalies	5 (11.9)	
<i>Hospitalization in the NICU after birth</i>	8 (22.9)	
<i>Surgery in the first month after birth</i>	6 (14.3)	
<hr/>		
Assessment time		
	<i>M (SD)</i>	<i>M (SD)</i>
<i>Gestational age at prenatal assessment</i>	27.9 (6.7)	25.9 (7.5)

(weeks)

Newborn's age at

postnatal assessment

1.7 (0.7)

1.6 (0.7)

(months)

Table 2. Maternal and paternal psychological distress and QoL: Descriptive statistics, correlations, group and gender effects

	Clinical group (<i>n</i> = 42 couples)			Comparison group (<i>n</i> = 42 couples)			Group effect (clinical vs. comparison)		Gender effect (mothers vs. fathers)			
	Mothers <i>M</i> (<i>SD</i>)	Fathers <i>M</i> (<i>SD</i>)	<i>r</i>	Total <i>M</i> (<i>SD</i>)	Mothers <i>M</i> (<i>SD</i>)	Fathers <i>M</i> (<i>SD</i>)	<i>r</i>	Total <i>M</i> (<i>SD</i>)	<i>F</i>	η^2	<i>F</i>	η^2
<i>Psychological distress (BSI-18)</i>												
Anxiety	7.1 (5.2)	5.5 (5.3)	.63***	6.3 (5.3)	4.9 (3.2)	3.6 (3.2)	.33*	4.2 (3.2)	5.85*	.068	7.41**	.085
Depression	6.1 (5.3)	4.3 (4.5)	.50**	5.2 (5.0)	3.3 (2.6)	1.9 (2.2)	.09	2.6 (2.5)	12.58**	.136	14.74***	.156
<i>Quality of Life (WHOQOL-Bref)</i>												
Physical	70.9 (11.9)	77.1 (12.2)	.17	74.0 (12.3)	67.1 (15.2)	81.1 (10.9)	.27	74.1 (14.9)	0.02	.000	33.28***	.291
Psychological	73.4 (12.6)	77.2 (14.3)	.42**	75.3 (13.6)	73.6 (13.3)	82.3 (10.6)	.09	77.9 (12.7)	1.43	.017	13.81***	.146
Social Relationships	75.6 (12.4)	74.2 (14.9)	.52**	74.9 (13.6)	77.5 (17.8)	77.7 (13.8)	.52***	77.8 (15.7)	0.89	.011	0.14	.002
Environment	70.1 (11.1)	65.5 (11.2)	.59***	67.8 (11.3)	69.4 (11.3)	71.4 (11.8)	.45**	70.4 (11.5)	1.42	0.17	1.18	.014

p* < .05, ** *p* < .01, **p* < .001