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Medical information concerning the infant's congenital anomaly: The role of parents' information perceptions on parental adjustment during the transition to parenthood

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Abstract

Background: When a diagnosis of congenital anomaly (CA) is made, parents are confronted with new and complex medical information, which may impact their parental adjustment. However, few studies have explored the role of information concerning the CA in parental adjustment, during the transition to parenthood.

Objective/Hypothesis: This study aimed to characterize both parents' perceptions of information concerning the CA and to investigate their role in maternal and paternal adjustment, one month after the disclosure and six months post-birth.

Methods: Thirty six couples whose infants were prenatally- or postnatally diagnosed with a CA participated in this prospective longitudinal study. During both assessment times (Time 1: one-month after the disclosure; Time 2: six-month post-birth), they answered the Brief Symptom Inventory-18, the EUROHIS-QOL-8, and other specific questions to assess parents' information perceptions.

Results: Mothers were more satisfied than fathers ($p < .01$) with the amount of information that was received at the disclosure, although mothers and fathers reported similar levels of comprehension of information. Six-month post-birth, both parents were similarly satisfied with the information that was received, although mothers sought significantly more ($p < .01$) additional information. Both maternal and paternal adjustment were significantly associated with maternal perceptions of information concerning CA.

Conclusion: Health professionals should recognize the important role of information concerning CA in parental adjustment and tailor their communication practices in order to promote parents' satisfaction and comprehension of the medical information. Despite the prominent influence of maternal perceptions on parental adjustment, both parents should be included in the communication process.

Key-words: comprehension of information, diagnosis of congenital anomaly, parental adjustment, parents' information perceptions, satisfaction with information.

Introduction

Congenital anomalies (CA), the leading cause of infant mortality and morbidity, are structural or functional anomalies present at birth(1). After the disclosure of the infant's diagnosis, information (e.g., CA type, prognosis, treatment options and caregiving demands, 2,3) is needed and valued by parents(4,5), because it helps parents make sense of the event and adjust their expectations about the future.

When first learning about their infant's CA, the majority of parents have poor prior knowledge about the type of CA(6,7). One study showed that 100% of mothers and 97% of fathers had never heard about the CA before the disclosure (2), which suggests that parents are often faced with new and complex medical information. Moreover, the lack of prior knowledge about the CA can intensify parents' negative emotional reactions at the disclosure (2,8-9), although no studies have examined the impact of the parents' lack of prior knowledge on parental adjustment.

Concerning the information about the CA, two variables that seem to be particularly important include parents' comprehension and parents' satisfaction with the amount of information that is given. Research shows that parents' comprehension of the information about the CA may be compromised by the emotional impact of the disclosure, which is often characterized by intense and negative emotions (10,11). For example, in one study, most parents only understood 40-60% of the information presented at the disclosure (8). In another study, 33% of parents reported having understood less than half of the information given at the disclosure (7). There is some evidence, which is grounded in qualitative design studies, that problems in gathering comprehensive and clear information about the diagnosis are

associated with parental feelings of distress, confusion and frustration (12). Mothers reported that their well-being after the disclosure depended on whether or not they had difficulties in understanding the medical information (13). However, further research is needed in order to examine the specific impact of the comprehension of the information on both parents' individual adjustments.

Concerning the information that is given by health professionals about the infant's CA, not all parents are satisfied with receiving the same amount of information; most parents report that they prefer to receive a great amount of information about their infant's CA(14-16), although a few parents report ambivalence concerning the amount of information that they want to receive(3), or prefer to receive little information about their infant's CA(17). Parents' satisfaction with the amount of information given may be dependent on parents' needs, preferences, and preparedness for understanding the information concerning the CA(3,17-18). Furthermore, there is evidence that the alignment between the parents' preferences and the amount of information that is given (i.e., parents' satisfaction) may influence their adjustment. When parents feel dissatisfied with the amount of information given at the disclosure, increased levels of anxiety(19) and frustration(18) may arise. Moreover, mothers with a high preference for information about their infant's CA experience a higher sense of control and security when they actively seek information after the disclosure. Conversely, mothers with a low preference for information about their infant's CA report high levels of anxiety when they are given additional information about the CA(17). However, the existing evidence is grounded in qualitative studies, so further studies are needed in order to specifically explore the association between parents' perceptions of satisfaction with the information given and their adjustment in the early post-diagnosis stage, as well as after the infant's birth, which is an unexplored topic. In fact, although there is evidence that parents often actively seek additional information after the disclosure (4), even

when they considered the initial information to be sufficient (13), there were no studies that explored parents' perceptions of information during the first months after the birth of an infant with a CA.

In sum, although existing research highlights the role of information about the CA in parents' adjustment, the methodological limitations of most studies (e.g., qualitative design, women-only samples, retrospective and cross-sectional data collection,16-17) do not allow for a thorough understanding of the role of parents' perceptions of the information concerning the CA in their adjustment during their transition to parenthood. Additionally, the results on this topic are influenced by parents' socio-cultural background(20), so the generalization of the results to other cultural contexts, such as Portugal, where no prior studies on this topic were conducted, should be cautious. Moreover, because both members of the couple share the experience of receiving a prenatal- or postnatal diagnosis of the CA(10), it is possible that one parent's perceptions influence the other parent's perceptions of the information about the CA and, consequently, their adjustment. However, to our knowledge, this topic has not been previously explored.

The present study aimed: 1) to characterize both parents' perceptions of the information concerning their infant's CA (prior to the disclosure, at the disclosure and six months post-birth) and 2) to investigate the role of both parents' information perceptions on maternal and paternal adjustment (psychological distress and quality of life [QoL]) one month after the disclosure and six months post-birth.

Methods

Participants and procedures

This study was approved by the Ethics Committees of the Hospitais da Universidade de Coimbra and Centro Hospitalar de Coimbra, Portugal. Inclusion criteria for the study included: having an infant who was prenatally- or postnatally diagnosed with a CA, being at least 18 years of age and having a level of literacy that permitted comprehension of the assessment protocol. Data collection occurred between September 2009 and February 2012. Approximately one month after the disclosure of the diagnosis, all of the parents who met the inclusion criteria were approached by the researchers at the end of a medical appointment (consecutive sample). The research goals were presented, and those parents who decided to participate signed an informed consent form, were given the questionnaires (Time 1-T1) and were asked to return them during the next medical appointment. A total of 82 couples were contacted, of whom 22 refused to participate/did not return the questionnaires (participation rate: 73.2%). Six-months post-birth (Time 2-T2), parents were mailed the questionnaires, along with a pre-stamped envelope in which to return them after completion. At T2, 17 couples did not return the questionnaires (attrition rate: 28.3%), and seven questionnaires were excluded because they had only been completed by the mother. No significant differences in socio-demographic or clinical characteristics were found between participants and dropouts at T2 (data not shown). The final sample consisted of 36 couples, who answered the questionnaires at T1 and T2.

The sample characteristics are presented in Table 1.

[Insert_Table_1_about_here]

Measures

Socio-demographic and clinical information. Socio-demographic (gender, age, educational level, professional status) and the infant's clinical information (timing of diagnosis, type of CA, hospitalization, need for surgery) were collected with self-report forms.

Information perceptions. Information perceptions were assessed by questions that were specifically developed for this study, based on prior existing studies, and were answered on a dichotomous scale (yes, no) or on visual analogue scales (VAS). VAS are used to measure constructs that are believed to vary within a continuum of values, which allows for the maximization of sensitivity (respondents are less likely to feel that the scale lacks an option that characterizes their perceptions)(21). The perception of information prior to the disclosure was assessed with two questions: 1) *“Had you ever heard of the CA diagnosed to your infant?”*, yes vs. no; 2) *“Prior to the disclosure, what amount of information did you have about the CA?”*, (0= None to 100= A lot).

The perception of information at the disclosure was assessed with two questions, concerning parents' comprehension of the information (*“To what extent did you understand the information about the CA (e.g., characteristics, prognosis, treatment options) received at the disclosure?”*; 0= Not at all to 100= Completely) and the satisfaction with the information given (*“How satisfied are you with the amount of information about the CA (e.g., characteristics, prognosis, treatment options) given at the disclosure?”*; 0= Not at all to 100= Very).

The perception of information six months post-birth was evaluated with three questions: 1) *“Since the disclosure, to what extent have you sought additional information about the CA?”* (0= Not at all to 100= A lot); 2) *“Since the disclosure, did you obtain*

additional information about the CA (e.g., prognosis, treatment options)?” (yes vs. no); 3) *“How satisfied are you with the information about the CA that you got since the disclosure?”* (0= *Not at all* to 100= *Very*).

Psychological distress. The Portuguese version of the Brief Symptom Inventory-18(22) consists of 18 items, which are answered through the use of a 5-point Likert scale from 0 (*Not at all*) to 4 (*Extremely*). It includes three dimensions: Anxiety, Depression, and Somatization (only Anxiety and Depression dimensions are used in this study). Higher scores indicate more intense psychopathological symptoms. Cronbach’s alphas in our sample ranged from .87 (Depression-mothers, T1) to .95 (Anxiety-fathers, T2).

QoL. The Portuguese version of the EUROHIS-QOL-8(23) consists of 8 items, which are answered through the use of 5-point Likert scales (e.g., from 1= *Very unsatisfied* to 5= *Very satisfied*), that form a global score. Higher scores indicate a better QoL. In our sample, Cronbach’s alphas ranged from .75 (mothers-T1) to .88 (mothers-T2).

Data analyses

Analyses were conducted with IBM SPSS (version 19.0). Descriptive statistics and comparison tests (chi-squared tests, *t* tests and Mann-Whitney U tests) were used to describe and compare sample characteristics and parents’ perceptions of information concerning the CA. Spearman correlations were used to examine the associations between parents’ information perceptions. Pearson partial correlations were used to examine the associations between each parent’s information perception (controlling for the remaining perceptions and for parents’ perceived severity of the infant’s CA) and parental adjustment. Significance was defined as $p < .05$, but marginally significant ($p < .10$) effects are also reported. Effect-size measures are presented for the comparison analyses (small: $d \geq .20$; $\Phi \geq .10$; medium: $d \geq .50$; $\Phi \geq .30$; large: $d \geq .80$; $\Phi \geq .50$).

Results

Parents' perception of information concerning the CA

Table 2 presents results concerning parents' perceptions of information about the CA. Most parents had never heard about the CA prior to the disclosure, and among those who had heard about the CA, information levels were similarly low for both genders ($Z = -0.79, p = .432$).

[Insert_Table_2_about_here]

At the disclosure, mothers were significantly more satisfied than fathers with the amount of information given by health professionals, but no differences were found concerning comprehension levels, which were moderately high for both genders. Moreover, mothers who were more satisfied with the amount of information that was given reported higher comprehension levels ($\rho = .549, p = .001$); this relationship was not found for the fathers ($\rho = .157, p = .360$).

Six-month post-birth, mothers reported having sought for significantly more information about the CA than their partners, although both genders obtained additional information about their infant's CA. A relationship between search for information and additional information was found for mothers ($\rho = .399, p = .016$), but not for fathers ($\rho = .157, p = .361$). No association was found between search for information and satisfaction with the additional information (mothers: $\rho = .261, p = .125$; fathers: $\rho = .053, p = .758$). Mothers and fathers were similarly satisfied with the additional information. From the disclosure to six months post-birth, a significant increase in satisfaction levels was found for fathers ($t_{35} = -4.30, p < .001$), but not for mothers ($t_{35} = -0.75, p = .459$).

The impact of parents' perception of information about the CA on adjustment

Table 3 presents the correlation coefficients between parents' information perceptions and individual adjustment one-month after the disclosure and six-months post-birth, while controlling for the perceived severity of the infant's CA.

[Insert_Table_3_about_here]

One month after the disclosure

Mothers with prior knowledge of their infant's CA reported higher levels of anxiety and depressive symptoms, and their partners also presented higher levels of anxiety and depression. Moreover, mothers' higher satisfaction and lower comprehension levels at the disclosure were associated with worse maternal and paternal adjustment. Paternal comprehension levels did not affect fathers' individual adjustment.

Six-month post-birth

When both partners sought additional information, and the mothers felt less satisfied, their adjustment was worse. Mothers' search for information was negatively associated with their partner's QoL.

Discussion

Our findings support the important role of information about the CA for Portuguese parents and are innovative because they highlight the following: a) gender differences in the perceptions of information about the CA, with mothers being significantly more satisfied than their partners with the information that is given at the disclosure (but not six-months post-birth); b) the differential impact of the information perceptions on both parents' individual adjustment at the disclosure of the diagnosis, as well as during the transition to parenthood; c) mothers' information perceptions influence their own adjustment, as well as their partner's individual adjustment, which suggests that there are important mutual influences within the couple.

Similar to other studies(2), most parents in our sample had no prior knowledge about the CA; because medical information is often unexpected, it may be difficult to understand. However, mothers with prior knowledge of the CA displayed worse adjustment one-month post-diagnosis. These mothers may be more aware about the caregiving demands that are associated with the CA, although prior information may be either realistic or biased. Moreover, these mothers may perceive their infant's CA as a failure of their protective role(24), and feel guilt and frustration⁹ which can lead to worse adjustment.

Both parents reported moderately high levels of comprehension of the information about the CA, and for mothers, this was associated with better adjustment, as suggested in other studies(13), as well as with higher satisfaction with the information that is received. This is consistent with the idea that satisfaction with the information may be dependent on the parents' ability to understand it(18).

Mothers were moderately satisfied with the information that was given, both at the disclosure and six months post-birth, but the effects of their satisfaction on adjustment were

different over time: higher satisfaction was associated with worse adjustment one-month post-disclosure, and with better adjustment six-month post-birth. The relationship between satisfaction and adjustment post-disclosure contradicts the findings of existing research(18), but this may be because previous studies have not controlled the role of comprehension of information. The information that is received at the disclosure, despite being perceived as satisfactory in terms of quantity, fosters uncertainty about the future and has a strong emotional impact(10), and may not be comprehended immediately after the disclosure, which can result in poorer adjustment post-disclosure. However, six-month post-birth, satisfaction with the information that was given may result in a greater maternal sense of control and, consequently, in the selection of useful strategies that can be used to cope with the infant's diagnosis(25), which translates into better adjustment. Consistently, mothers reported worse adjustment when they sought for additional information about the CA, which suggests that they may not perceive the existing information as sufficient to regain a sense of control and to handle the situation(25).

Moreover, our results show important gender differences concerning satisfaction with the information that is given at the disclosure and six-months post-birth. First, we found that mothers were significantly more satisfied with the information that is given at the disclosure than their partners, but they also sought for significantly more additional information after the infant's birth. On the other hand, fathers, rather than mothers, showed a significant increase in satisfaction levels with the information that is given from post-disclosure to post-birth. Second, whereas mothers' adjustment is mostly influenced by their own perceptions, paternal adjustment is influenced by their partner's perceptions, rather than their own perceptions. This may be due to the different roles that are adopted during the transition to parenthood. Information needs may be more prominent for mothers, who usually assume the caregiving tasks, than for fathers, who are the family providers(26-27). Moreover, due to professional

constraints, fathers may not always be present at the medical appointments, so they may leave the responsibility of obtaining and understanding the medical information concerning the infant's CA to the mothers. However, despite fathers reporting that they sought less information than mothers, the sharing of information within the couple seems to help fathers feel more satisfied with the information about the CA, over time.

Furthermore, our results suggest mutual influences within the couple(28). Specifically, when maternal perceptions negatively impact their own adjustment, negative couple interactions may occur (e.g., conflict), which causes paternal preoccupation(29) and worse paternal adjustment. Additionally, mothers may feel more insecure when their partners report less comprehension and more search for information about the infant's CA, which results in worse maternal adjustment.

In sum, although interesting and, in general, consistent with studies conducted in other countries, this study was conducted in the Portuguese population. Therefore, the generalization of its findings to other populations should be cautious, given the influence of socio-cultural and religious aspects in how couples experience their infant's CA diagnosis(20). Moreover, this study has some limitations, namely the study's reduced power to detect small effects due to its sample size, the use of questions that were developed by the authors to assess parents' information perceptions, and the fact that the statistical analyses (correlations) only allow for the establishment of associations between variables, and not the establishment of causal relationships. Moreover, although there were no significant differences between the participants and the dropouts, ethical constraints prevented us from collecting the socio-demographic and clinical data of non-participants. Due to this, despite having used a consecutive sampling technique, it is not possible to completely ensure the representativeness of the sample.

Conclusions

Health professionals should recognize the important role of information concerning the CA in parental adjustment and tailor their communication practices in order to promote parents' satisfaction and comprehension of the medical information. In fact, some specific clinical implications can be derived from the findings of this exploratory study. First, health professionals should include both mothers and fathers in the process of communicating information about the CA. Prior studies have highlighted that the paternal experience should not be ignored by health professionals(10). Being attentive to the couple's dynamics and to the influence that one parent's perceptions seem to exert on the other parent's adjustment is of paramount importance to promote adjustment of both partners. The opportunity to express their opinions, concerns and emotions regarding the CA in a safe and nonthreatening environment should be given to both parents, as a couple and individually.

Second, in order to promote satisfaction with the information, health professionals should assess parents' information needs and meet them by providing an adequate quantity of information and tailoring the information to the parents' preparedness and comprehension skills, at the disclosure of the diagnosis, as well as over time. Third, it is important to assess parents' prior knowledge of the CA, clarify potentially incorrect information, build on the parents' prior knowledge, and provide new information about the CA. Fourth, in order to promote the parents' comprehension of the information, it is important to provide specific and clear information in several formats (e.g., written information)(24), repeat relevant information at different moments of clinical care, encourage the placement of doubts, and obtain feedback from the parents about what was understood. Finally, it is important to help parents develop strategies to cope with the information that is received over time (e.g., promote the balance between problem-focused and emotion-focused coping strategies).

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Table 1 - Sample socio-demographic and clinical characteristics

Socio-demographic characteristics				
	Mothers	Fathers		
	(<i>n</i> = 36)	(<i>n</i> = 36)		
	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>t</i>	<i>d</i>
<i>Age (years)</i>	31.72 (4.31)	33.25 (5.05)	-1.38	0.33
<i>Educational level (years)</i>	14.67 (3.28)	12.11 (2.73)	3.56**	0.85
	<i>n</i> (%)	<i>n</i> (%)	χ^2	Φ
<i>Professional status</i>				
Employed	32 (88.9)	33 (91.7)	0.16	-.05
Unemployed	4 (11.1)	3 (8.3)		
CA characteristics				
Infant's data (<i>n</i> = 36)				
<i>n</i> (%)				
<i>Timing of diagnosis</i>				
Prenatal		21 (58.3)		
Postnatal		15 (41.7)		
<i>Type of congenital anomaly</i>				
Congenital heart disease		14 (38.9)		
Nervous system anomalies		3 (8.3)		
Digestive system anomalies		3 (8.3)		
Urinary system anomalies		10 (27.8)		
Oro-facial clefts		3 (8.3)		
Limb anomalies		3 (8.3)		
<i>Hospitalization</i>				

	Yes	16 (44.4)
	No	20 (55.6)
<i>Need for surgery</i>		
	Yes	11 (30.6)
	No	25 (69.4)

** $p < .01$

Table 2 – Maternal and paternal perceptions of information concerning the CA

	Mothers	Fathers	χ^2/ t	Φ/ d
	(<i>n</i> = 36)	(<i>n</i> = 36)		
	<i>n</i> (%) /	<i>n</i> (%) /		
	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)		
Information prior to the disclosure				
<i>Prior knowledge of the CA</i>				
Yes	17 (47.2)	14 (38.9)	.510	0.08
No	19 (52.8)	22 (61.1)		
<i>Prior level of information</i>	9.86 (14.42)	8.27 (12.44)		
Information at the disclosure				
<i>Satisfaction</i>	62.99 (17.6)	53.71 (20.4)	2.63*	0.49
<i>Comprehension</i>	71.35 (19.22)	72.63 (19.21)	-0.43	0.07
Information six months post-birth				
<i>Search for additional information</i>	50.28 (35.28)	35.22 (36.11)	2.61*	0.42
<i>Additional information</i>				
Yes	26 (72.2%)	29 (80.6%)	.69	0.10
No	10 (27.8%)	7 (19.4%)		
<i>Satisfaction</i>	66.12 (23.17)	69.81 (17.02)	-1.03	0.18

**p* < .01

Table 3 – Partial correlations between maternal and paternal perceptions of information about the CA and maternal and paternal individual adjustment

Individual adjustment						
<i>One month after the disclosure</i>	Maternal			Paternal		
	Anxiety	Depression	QoL	Anxiety	Depression	QoL
<i>Prior knowledge of the CA – mother^a</i>	.35*	.32 ⁺	.02	.29 ⁺	.45**	-.09
<i>Prior knowledge of the CA – father^a</i>	.26	.21	.10	.09	.16	-.16
<i>Satisfaction at the disclosure – mother^b</i>	.43*	.43*	-.03	.34 ⁺	.32 ⁺	-.21
<i>Satisfaction at the disclosure – father^b</i>	.21	.11	-.12	.15	.08	.07
<i>Comprehension at the disclosure – mother^c</i>	-.36*	-.45**	.21	-.33 ⁺	-.39**	.40*
<i>Comprehension at the disclosure – father^c</i>	-.18	-.28	.21	-.05	.05	-.14
<i>Six months post-birth</i>	Maternal			Paternal		
	Anxiety	Depression	QoL	Anxiety	Depression	QoL
<i>Search for additional information – mother^d</i>	.37*	.34 ⁺	-.18	.09	.11	-.41*
<i>Search for additional information – father^d</i>	.36*	.37*	-.12	.31 ⁺	.28	-.16
<i>Additional information – mother^e</i>	-.15	-.08	.10	-.05	-.01	.23

<i>Additional information – father^e</i>	-0.22	-0.12	-0.05	-0.10	-0.10	-0.03
<i>Satisfaction with additional information – mother^f</i>	-0.28	-0.31 ⁺	.42 [*]	.04	.04	.21
<i>Satisfaction with additional information – father^f</i>	.01	-0.06	.18	.01	-0.08	.23

⁺ $p < .10$. ^{*} $p < .05$. ^{**} $p < .01$

^a Controlling for perceived severity of the diagnosis; ^b Controlling for perceived severity of the diagnosis and comprehension at the disclosure. ^c Controlling for perceived severity of the diagnosis and satisfaction at the disclosure. ^d Controlling for perceived severity of the diagnosis, additional information and satisfaction with additional information. ^e Controlling for perceived severity of the diagnosis, search for additional information and satisfaction with additional information. ^f Controlling for perceived severity of the diagnosis, search for additional information and additional information.