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ORIGINAL ARTICLE

Antenatal diagnosis of congenital anomaly: a really traumatic experience?

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Objective: With increasing use of routine prenatal ultrasound, prenatal counseling after diagnosis of congenital malformations is frequently offered to prospective parents. We aimed to assess if the communication of diagnosis of a congenital anomaly in the fetus meets American Psychiatric Association (APA) criteria for trauma in parents.

Study Design: In the period ranging from 2003 to 2009 a preliminary investigation was conducted with 165 prospective mothers and 91 prospective fathers being interviewed after communication of diagnosis. Analysis of statements was made independently by two psychologists considering the APA definition of trauma.

Result: A total of 145 mothers and 76 fathers experienced the communication of diagnosis in their fetus as a traumatic event. There was no correlation between type of malformation and trauma nor was there statistical difference between mother and father regarding the stressor.

Conclusion: Communication of diagnosis of a fetal anomaly can be a traumatic event and should be dealt with consequently. Given the therapeutic value of sharing traumatic experience such practice should be encouraged as part of the consultation process.
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Introduction

Although antenatal diagnosis is undoubtedly a stressful experience, it differs from more widely studied 'traumas' such as severe burns, automobile accidents and sexual assaults.

According to the American Psychiatric Association (1994 APA)[1] a traumatic event has a number of characteristics: it happens suddenly and unexpectedly, it disrupts beliefs, values and one's basic assumptions about the world and others. The stressor is usually experienced with intensity, terror and helplessness. In the immediate period after the event the person may experience numbness, emotional release, express anger, loss, concern and hyperarousal. It is well known that the degree to which events are experienced as traumatic may be mediated by age, religious faith and individual interpretation. Among individuals who neither experience an acute emotional response nor interpret a potential stressor as extremely disturbing and frightening, the likelihood of developing post traumatic stress disorder is very low. Recently a few studies have assessed that unexpected admission of a child to a PICU is a stressful event associated with parental post traumatic stress. Researchers have proposed post traumatic stress disorder as a model to explain the psychological reaction of parents to their NICU experience.[2–7]

A pilot study was conducted to assess if the communication of diagnosis of a congenital anomaly in the fetus meets APA criterion for trauma.

Methods

In the period ranging from 2003 to 2009 all couples attending Prenatal Consultation Service at our Institution were offered an interview with a psychologist in the first month after communication of diagnosis as part of counseling strategy.

Couples were first informed of the underlying pathology by the gynecologist performing ultrasound. Couples were then referred to our prenatal consultation service where a pediatric surgeon, neonatologist and a psychologist provided them with extensive information about prenatal and postnatal evolution of the malformation, expected length of hospital stay, mode and time of delivery, possible complications in utero and after birth; quality of life was also addressed. Multidisciplinary team was available to the couple on ongoing basis to assist with their questions and concerns.

Interviews were focused on parents' accounts of cognitive and emotional reactions since communication of diagnosis. Each

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member of the couple was interviewed separately. Interviews were recorded and transcribed.

Transcription was independently reviewed by two psychologists who did not participate in prenatal consultations.

Analysis of statements was made considering the definition of traumatic event given by the American Psychiatric Association. We considered experiencing the communication of diagnosis as a traumatic event in presence of the following: (1) it was reported as sudden and unexpected, (2) it disrupted beliefs, values and basic assumptions about the world and others, (3) the subject experienced the stressor with intensity and/or terror, and/or helplessness, (4) at the time of experiencing the traumatic event the subject felt numb and/or experienced emotional release and/or express anger and/or loss and/or concern and/or hyperarousal. The subject was considered having experienced a trauma only if the two psychologists were in agreement. Correlation was sought between trauma and type of malformation with the Fisher's exact test. McNemar test was used to assess differences between each couple.

Results

Over a 6-year period, 91 couples agreed to participate. In 74 couples only the mother agreed to participate. Thus, the total responders were 165 mothers and 91 fathers. All individuals were of Caucasian origin. The fetuses were affected by the following anomalies: 47 cystic adenomatoid malformation of the lung (CALM), 63 congenital diaphragmatic hernia, 36 abdominal wall defects and intestinal atresia, and 19 abdominal cysts. Parents' age and gestational age at diagnosis are reported in Supplementary Table 1. Educational background, current job status and parity are reported in Supplementary Table 2.

None of the couples decided to terminate their pregnancy. A total of 145 (88%) mothers out of 165 and 76 (83%) fathers out of 91 experienced antenatal diagnosis as a traumatic event. Communication of diagnosis was perceived as a trauma as follows: 42 mothers and 20 fathers in CCAM, 56 mothers and 29 fathers in congenital diaphragmatic hernia, 30 mothers and 18 fathers in intestinal atresia, and 17 mothers and 9 fathers in cystic abdominal lesions (Table 1).

There was no correlation between type of malformation and trauma ($P = 0.8$) and there was no statistical difference between mother and father regarding the stressor ($P = 0.4049$). The two psychologists were not in agreement as to whether the experience was traumatic or not in nine cases.

Table 1 Percentage of mothers' and fathers' trauma by type of malformation

	Mothers' trauma				P *value*	*Fathers' trauma*				P *value*
	No		*Yes*			*No*		*Yes*		
	N	*(%)*	N	*(%)*		N	*(%)*	N	*(%)*	
Kind of pathology										
CCAM	5	(10.6)	42	(89.4)		3	(13.0)	20	(87.0)	
CDH	7	(11.1)	56	(88.9)		5	(14.7)	29	(85.3)	
IA	6	(16.7)	30	(83.3)	0.8	4	(18.2)	18	(81.8)	0.8
Cystic	2	(10.5)	17	(89.5)		3	(25.0)	9	(75.0)	
Total	20	(12.1)	145	(87.9)		15	(16.5)	76	(83.5)	

Abbreviations: CCAM, congenital cystic adenomatoid malformation of the lungs; CDH, congenital diaphragmatic hernia; IA, intestinal atresia.

Discussion

Diagnosis of a fetal malformation places a burden of uncertainty on parents and entails a variety of losses for couples, including loss of the joy of pregnancy, the dreamed child and the world as they knew it.[8–10]

Psychological effects of antenatal diagnosis are long established: in particular, Leithner[11–13] found that acute distress is not only experienced by women with proven fetal malformations or genetic disorder but also by those with diagnosis of a sonographic sign; Kemp[14] and Aite[15] found that counseling by specialist staff reduce levels of parental anxiety associated with the diagnosis of fetal surgical malformation. Moreover, Hunfeld[16] described increased family burden and grief 1 year after birth, whereas Skari[17] reported that prenatal diagnosis of congenital malformations was a significant independent predictor of acute parental psychological distress after birth. However, none of these papers have taken into consideration discovering a fetal malformation as a traumatic event: this would allow to consider commonly adopted psychological interventions for trauma at the time of consultation as well as throughout pregnancy. In this respect, a single session debriefing is standard clinical practice after traumatic events even if there is no consensus on whether a session debriefing can contribute to prevention of post traumatic stress disorder.[18,19]

In our sample, communication of diagnosis was really sudden and unexpected without any previous suspicion of disease for 145 mothers and 76 fathers. This complies with the first APA criterion for trauma for which the subject has to experience the event as sudden and unexpected.

Theoretical accounts of the psychology of pregnancy suggest that there is growing affection for the unborn child during pregnancy.[20–23] It is well known that parents fantasized about themselves as parents and their unborn baby.

By reviewing interviews we noted that discovering a fetal malformation causes the loss of the expected perfect child as well as the loss of plans and fantasies regarding their being parents of a normal healthy child, disrupting their assumptions regarding parenthood and birth. This is in agreement with the second APA criterion for which the event is traumatic, if it disrupts the subject's beliefs and basic assumptions about life. The impact of such knowledge on women's feelings regarding their pregnancies and on

their relationships with their infant after birth remains unclear.[24,25]

A total of 145 mothers and 76 fathers experienced the stressor with intensity and/or terror and/or helplessness. According to parents' descriptions of their experience the two independent reviewers felt that the third APA criterion for trauma was fulfilled. Of interest, only 17 mothers and nine fathers did not report such perception of the stressor; despite such percentage is very small, this emphasizes that communication of diagnosis cannot be defined a traumatic event *a priori*.

All mothers and 76 fathers felt numb and therefore did not know how to respond and experienced the communication of diagnosis with anger and/or emotional release and /or concern and/or loss and/or hyperarousal. In this regard the most frequent expression used by prospective parents was as follows: 'I was numb with fright'. According to two psychologists only eight mothers and seven fathers did not report such experience at the time of communication of diagnosis. Psychological features of this small subset of parents would probably deserve further analysis.

The fact that there was no correlation between type of diagnosis and trauma suggests that regardless of the severity of the anomaly diagnosed, communication of diagnosis can be traumatic *per se*. In this respect it must be emphasized that we investigated potentially lethal conditions as well as simple-to-fix anomalies and it turned out that these were equally traumatic. In other words, distress experienced by prospective parents at communication of diagnosis does not appear to vary as a function of the anomaly.

Moreover, according to our data it is clear that communication of diagnosis of a fetal anomaly can be a traumatic event for parents and, regardless of being father or mother, should be dealt with consequently. Therefore, as any traumatic event, at least a single session debriefing or non-directive counseling with psychologist should be offered to prospective parents soon after communication of diagnosis.[26–30] As trauma specialists have long asserted therapeutic value of sharing traumatic experience as crucial to recovery from psychological trauma,[31,32] collecting stories of traumatic experience should be encouraged as part of the consultation process.

These data emphasize need for collaboration between obstetrician-surgeons and mental health specialists in prenatal setting.

Our data seem to suggest that a session of non-directive counseling after communication of diagnosis can be used to assess if it was experienced as a trauma: whether or not this represents a possible means to prevent psychological morbidity, as reported in the literature, remains to be clarified. Further studies are needed to assess long-term effect of this counseling strategy on parents' affective state.

Conflict of interest

The authors declare no conflict of interest.

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Supplementary Information accompanies the paper on the Journal of Perinatology website (http://www.nature.com/jp)